



# ***Special care for sick babies – choice or chance?***

The BLISS baby report

No 1 – July 2005

putting babies first for 25 years



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## Foreword

With this report we are launching the BLISS Baby Charter for special care babies. It was developed using as a foundation the United Nations Convention on the Rights of the Child for its relevance to sick or premature babies.

The Charter recognises that babies are individual human beings, with all the rights and entitlements that humans of all ages enjoy. Whilst this may seem to be a statement of the obvious, our research and the experience of parents and babies shows that in important areas babies are not given the same consideration as children or adults.

We routinely carry out painful medical interventions on very young babies sometimes without any kind of pain relief or palliative measures. Sick babies are cared for in intensive care units staffed at levels so low that they would be not be tolerated in adult intensive care. We spend huge sums of money making sure that adults with cuts and bruises wait no more than four hours in their local A&E centre, whilst seeming to accept that life-saving treatment for sick babies may not be available locally, or even within one hundred miles of their place of birth.

The new agenda around patient choice holds significant promise for some parts of the health service but will do nothing for neonatal services unless money is allocated to improve the options available. When a baby in Bristol needs a cot and the nearest available are in London and Glasgow, this is not a choice worthy of the name.

Neonatal medical and nursing teams, whose unique combination of commitment and compassion saves thousands of lives a year, are working inside a system that is struggling to cope. This is not another exaggerated claim from an overly-anxious charity – the evidence of severe shortages of staff and cots uncovered by our research speaks for itself.

So is the Baby Charter an exercise in the obvious? Clearly it is not. It is a call to action for all those who want to make sure that people of all ages, including the very young, can rely on our health service to treat them fairly. We hope that our Baby Charter will help to make this aspiration a reality in all parts of the United Kingdom.



**Rob Williams**  
Chief Executive

## **The BLISS Baby Charter – for special care babies**

**Every baby in the United Kingdom regardless of race, religion or culture has the right to benefit from:**

- the same respect and dignity as adults
- the decisions affecting their care being made in their best interest
- the same level of specialist care as children and adults
- the same chances of survival as babies born in similar countries and circumstances
- the information and support needed by parents to help them care for their baby and achieve the best quality of life possible
- the opportunity to have their mother's breast milk when appropriate
- the necessary support and care after going home

## The BLISS Baby Charter – special care baby's version

1. I'm a real human being and I should be treated as an individual with respect and dignity just like any other human being, responding as much to my social and emotional needs, as to my medical needs.
  - by recognising that I can communicate my needs
  - by making me more comfortable and reducing stressful situations, which will help my development
2. Decisions about my future medical care should be focussed on my individual best interests.
3. I should have the same level of special nursing and medical care as children and grown ups, in my nearest specialist unit for the treatment I need.
  - If I need neonatal intensive care there should be 1:1 nursing care
  - There should be somewhere near the unit for my parents to stay overnight particularly if I am seriously ill
  - If I need to be transferred for neonatal intensive care, it should be to a unit within my neonatal network or where necessary to the nearest specialist unit
4. I should have the same chances of survival as other babies born in similar countries and circumstances.
5. I would like the nursing/medical team to tell my parents/carers all about my care. I would like the nursing/medical team to work together with my parents/carers to help make my time in special care less stressful, help my developmental needs and contribute to the best quality of life for me as possible.
  - by encouraging my parents to provide skin to skin contact and by supporting and encouraging them to touch me in a positive way
  - by reducing the bright lights and the noise to create quiet times during the day and night
  - by paying more attention to my needs for pain relief and for comforting me when I have painful procedures
  - by supporting my parents to recognise and respond when I am trying to communicate with them
6. It is best for me to have my mother's breast milk whenever possible and when appropriate.
  - My mum needs the maximum support to help provide breast milk and to breastfeed.
  - Breast milk is best for all babies but when you are born early or sick, it's really important. Sometimes it's difficult for mums of babies like me to establish breastfeeding so they need specialist breastfeeding counselling
  - By providing a comfortable and private place for my mum to express breast milk or to breastfeed
7. I and my parents/carers should receive the follow-up care and support I need when discharged home from hospital for me to have the best chance for a healthy future.
  - When I am discharged from hospital, there should be a care plan for my specific health or social care needs agreed between my parents/carers and community health professionals.
  - My parents/carers should have, or know how to access, support and information
  - I should have access to any special treatment, care or support necessary to ensure the best quality of life possible for me

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## 1. Executive Summary

This report details research we have commissioned into the acute health services available to newborn babies in the UK and also draws on high quality research done by others. The research, undertaken alongside our newly published Baby Charter for special care babies, reveals a system which is overstretched, under-resourced, and slow to respond to promising innovations in care.

### 1.1 Major areas of concern

- Neonatal services are so short of resources that nearly all units (95%) reported having taken in more babies than they were resourced or staffed for. Even though units are clearly prepared to stretch themselves, 72% of units had been forced to close to new admissions at least once in the last 6 months because they could not accept any more babies. This is leading to large numbers of babies having to be transferred many miles away from their local unit in order to find a cot.
- Staffing levels are low. Only 2% of units have reached the recommended level of one to one nursing in neonatal intensive care. Our research shows that the service needs up to 2,700 additional nurses to attain levels of staffing which the British Association of Perinatal Medicine considers to be safe. The funding shortfall is at least £75 million per year.
- A promising new baby focused approach to nursing babies, called developmental care, is only spreading at a slow rate through our neonatal units. Only 40% of units say they have identified a lead person for promoting developmental care and only 24% of units have anyone trained or being trained in the approach.
- Babies in neonatal care often suffer acute and chronic pain. Only 20% of units questioned regularly used a tool for assessing pain.
- This is all leading to the UK having some of the worst perinatal and infant mortality rates in Western Europe, even after statistical differences between countries have been ironed out. Mortality rates for babies and infants in the UK actually went up in 2003 for the first time in many years. Perinatal mortality figures for 2003 were the worst since 1996.
- Within the UK there are alarming variations in mortality rates. In parts of Scotland a baby is nearly three times more likely to die before its first birthday than in the South East of England.

### 1.2 Baby Charter Core Values: Key Findings

#### Core Value 1: The same respect and dignity as adults

##### Key findings:

- 40% of neonatal units that responded had a designated lead in charge of promoting and practicing the values of developmental care. However, only 24% of units had staff who were trained or receiving training
- Half of Type 3 units had a designated lead and a quarter of staff trained or in training whereas only a quarter of Type 1 units had a lead and 15% of staff in training

Developmental Care focuses on the baby by respecting their individual needs and responses. It is slowly being instituted throughout the UK but the pace of take up needs to increase. This survey indicates a low level of training amongst the practitioners. More investment in training and training time is essential if more babies and their parents are going to benefit from Developmental Care. The emerging neonatal networks should ensure that they have plans for introducing Developmental Care practice and training throughout their neonatal units.

## **Core Value 2: The decisions affecting their care being made in their best interest**

Every baby is an individual with individual circumstances. Decisions about their future care, which may be sometimes difficult to predict, should be made by their parents or carers, who are empowered by full and frank information, together with the medical and nursing team.

## **Core Value 3: The same level of specialist care as children and adults**

### **Key Findings**

- Approximately 2,275 extra WTE nurses are needed in units working in their current configuration to achieve 1:1 nursing care as recommended by BAPM
- Only 2% of units for which data were available were found to reach or be near the WTE nursing establishment to meet BAPM recommendation
- The extent of the current nursing shortfall against BAPM standards is greatest amongst Type 2 units

To achieve this core value it is necessary to have the correct number of medical and nursing staff. It is of grave concern that so many units are so far off the recommended nursing ratios. Trusts and Commissioners need to begin making commitments to increase their establishment and training places for this specialised area of nursing.

- 89% of units had overnight accommodation for mothers and 84% for both parents on site. However according to the parent survey 67% indicated that single accommodation was available to them and 52% that double accommodation was available to them. This discrepancy probably relates to accommodation not being vacant and thus not available to all who need it.

In a recent survey by BLISS, we could find little evidence that neonatal development funds were being invested in increasing and improving overnight accommodation for parents even though it is a DH recommendation. Investment in these important facilities for families must not be overlooked in favour of other areas of expenditure.

- 95% of units exceeded their cot capacity. 81% of Type 2 units exceed capacity in high dependency cots.
- 72% of units reported they had been closed to admissions in the previous six months. There were more closures in Type 2 and Type 3 units.
- 40% of parents surveyed had to travel up to 30 miles or more a day to visit their baby and 10% of couples paid £20 a day to travel to the unit.

It is alarming, although not unexpected, that so many units are running at over capacity and are having to close to new admissions. Furthermore, it is unacceptable that mothers and babies are continuing to be transferred around the country because local beds and cots cannot be found for them.

- In their current configuration there is a national vacancy rate of nurses of 8%
- All types of units mostly use their own staff to cover staff shortages

The current shortfall in nurses in post continues and this contributes to units closing to admissions to seriously ill babies. Whilst it is cheaper for units to use their own staff to cover these shortages, this is leading to tired and disenchanted nurses. More flexible working and family friendly working may help to attract returners and more creative ways of using all staff should be considered.

## **Core Value 4: the same chances of survival as babies born in similar countries and circumstances**

### **Key Findings**

- Perinatal, neonatal and infant mortality rates rose in the UK during 2003
- Wales has the lowest national infant mortality rate at 4.3



- West Midlands has the highest infant mortality rate, at 7.4, in England
- Scotland has some of the highest perinatal and infant mortality rates in the UK, peaking with Inverclyde with an infant mortality rate of 11.1
- After evening out data collection differences, the UK still does badly when compared with similar countries in Europe

It is imperative that action is taken both nationally and regionally to address these unacceptably high mortality rates. The Government indicated that the lives of 200 – 300 babies would be saved by their increased funding but to date there is no evidence of this.

### **Core Value 5: the information and support needed by parents to help them care for their baby and achieve the best quality of life possible**

#### **Key Findings**

- Parents surveyed indicated a duration of neonatal unit stay for babies ranging from 4 – 140 days
- 70% of units had limits about the presence of parents in the neonatal unit
- 25% of parents surveyed did not receive an information booklet about the neonatal unit and nearly 20% reported they did not receive general information leaflets
- Nearly 20% of units reported that they did not have access to an interpreting service

All units should be providing a wide range of information to support parents and families and to have arrangements in place to support families for whom English is not their first language. BLISS provides free information on all aspects of caring for babies needing neonatal care but not all neonatal units provide them for parents.

- Half the units surveyed use skin-to-skin contact (Kangaroo Care) and only a quarter use massage/gentle touch regularly. According to the parent survey only 26% regularly had skin-to-skin contact with their baby, 50% sometimes but 24% never
- 75% of both units and parents indicated a 'quiet time' took place during the day but only 58% of parents reported the use of incubator covers

It is disappointing that only half the units surveyed encouraged Kangaroo Care and particularly so that only 26% of parents had the benefit of it. To achieve this core value all units should have programmes in place to reduce the stress that babies go through whilst in neonatal care, particularly in intensive care.

- The use of a pain scale is only used by around 20% of units for chronic, acute and postoperative pain
- Less than 60% of units regularly use analgesia for pain relief. The most regularly used measures for comforting babies during painful procedures are gentle touch/holding, talking to baby and swaddling.

Adults and children would not be treated in this way. Reviewing pain relief practice has to be a priority for units and developing networks with the aim of developing protocols and guidance for staff.

### **Core Value 6: the opportunity to have their mother's breast milk when appropriate**

#### **Key findings**

- Only 29% of neonatal units reported having a specialist breastfeeding counsellor. The lowest indicated was 14% in Type 1 units
- Three-quarters of the parents surveyed were satisfied with the advice, help and support received.
- 95% of units indicated there was a place for expressing breast milk in privacy. However, 36% of parents did not feel they had enough privacy for breastfeeding

It is not good to see such a low provision of specialist breastfeeding counselling and that mothers did not feel they had the privacy needed. The needs of all mothers need to be addressed to ensure they are getting the support and encouragement needed.

### **Core Value 7: the necessary support and care after going home**

#### **Key findings**

- 60% of units reported they had a specific criteria for discharge home
- There is little concentration in the training curriculum of community health professionals, in particular Health Visitors who would visit the baby and parents when first home, about the care of the graduate prem and the support of parents
- Only 75% of surveyed units indicated that there was community based neonatal follow up for babies after discharge
- BLISS receives most calls to its Telephone Helpline from parents when their baby has been discharged home

It is particularly important to continue the support when at home so that the baby's development and quality of life is not compromised. To achieve this core value there needs to be more coordination between the hospital and community team and a review of the training curriculum for community health professionals.

#### **Funding The Future**

- If hospitals engage in networks at a 5:1 ratio, the gap in doctor's numbers between BAPM standards and current provision can almost be eliminated. However, there would a shortfall of nurses of around 2,700 which would cost about £75m per year.
- If networks do not achieve a ratio of 5:1 the shortfall in both doctors and nurses would be considerably more and the cost of filling the gap considerably increased
- Action is needed not only to increase nursing establishments but also to stimulate more to join, or rejoin, the nursing workforce.

## 2. Introduction

BLISS, the premature baby charity is dedicated to making sure that more babies born prematurely or sick in the United Kingdom survive and that each one has the best quality of life.

We aim to realise this by:

- Promoting new developments and innovations in care
- Supporting parents and families
- Campaigning for improvements in neonatal care

BLISS is the public advocate for babies born too soon, too small or too sick to cope on their own and thus is concerned that these vulnerable human beings get the care they deserve and need to enable them to achieve the best quality of life. In 1989, the United Nations Assembly adopted the Convention on the Rights of the Child. Although most of these rights apply from birth, we challenge the philosophy that sick, newborn babies are recognised as equal citizens and are being treated with equity not only to their older peers but to adults.

During its 25<sup>th</sup> Anniversary Year, BLISS is recognising and championing the rights of sick, newborn babies by launching the BLISS Baby Charter. This will encompass and represent a set of core values concerning sick, newborn babies and the care and equity they should receive and expect. It will provide a benchmark for improving neonatal care throughout the country and neonatal units will be asked to sign-up and display the Charter in their unit and strive to achieve the core values. Neonatal networks, Primary Care Trusts, professional organisations will also be asked to support the charter for their local babies.

From the values identified, an annual survey will be undertaken to establish progress, against a benchmark, in the care of babies against the Charter. This report, *Special care for sick babies – choice or chance?* is the first such annual survey.

## 3. Background

Over the past 25 years neonatal care, which is the care of premature and sick newborn babies, has developed from a highly technical specialism into an established sector of medicine. The increasing capability of nursing and medical care, supported by more sophisticated technology has led to a greater number of very small babies being born alive and surviving than was the case when BLISS was established. In the past, many such babies born prematurely or of very low birthweight would have died just after birth. For example, twenty years ago only 20% of babies weighing less than 1,000 gms (2lb 2oz) at birth survived but now about 80% survive. A recent report into babies born at 27/28 weeks gestation demonstrated an 88% survival rate<sup>1</sup> and a long term study of survival and developmental outcome has shown an 80% survival in babies born at 25 weeks and 72% survival of babies born at 24 weeks<sup>2</sup>.

Currently around 12% of all babies born in the UK (approximately 80,000) need some level of special care and around 2.5% of all babies (approximately 18,000) need the highest level of intensive care. For more figures and definitions see Appendix I.

As the effectiveness of neonatal care has developed, along with other factors, demand has grown because of:

- increasing survival and more babies needing intensive care cots, together with longer stays for extremely premature infants
- better obstetric identification of problems with the baby whilst still in the womb with an increasing likelihood of baby being delivered before problems worsen
- more women are having their babies later in life which increases the risk of obstetric complications and/or premature birth
- an increase in the rate of multiple births, often due to fertility treatment. Multiple pregnancies are more likely to result in premature birth
- this country having the highest rate of teenage pregnancies in Europe and again these pregnancies are at high risk of resulting in a premature or low birthweight baby.

However, funding and the organisation of care had not kept up with this increasing demand on neonatal care which has led the service to the brink of collapse. In addition, when compared to other Western

European countries, the UK appears to have a much worse survival rate for babies and infants. Although it has now been recognised that the data is collected differently throughout Europe even when the inconsistencies are taken into account, the UK is still doing badly. There was an increasing number of haphazard transfers of mothers with threatening premature birth or babies born prematurely or sick, often hundreds of miles away from home, because units are closed to admission. This led many organisations such as the British Association of Perinatal Medicine (BAPM), the Neonatal Nurses Association, the Confidential Enquiry into Stillbirth and Deaths in Infancy and BLISS to call for a government review into the way these services were provided and organised.

The aim of the review, led by the Department of Health (DH), which took place during 2001/02 was to assess the challenges facing neonatal care in England and its ability to expand and develop the service to meet the increasing demand. The Review was informed by an expert advisory group from neonatal paediatrics, neonatal nursing, specialist health commissioning, obstetrics and midwifery, as well as BLISS representing the views and needs of parents and babies.

In April 2003, the Department of Health (DH) published the results of this review as a consultation document called "*The Neonatal Intensive Care Review – strategy for improvement*"<sup>3</sup>. The consultation document proposed a more structured, joint approach to care for sick, newborn babies with hospitals working more closely together as an integrated team in managed clinical networks. This proposal supported the recommendations for such networks from professional bodies such as the British Association of Perinatal Medicine (BAPM) who had published their revised standards for neonatal care in 2001<sup>4</sup>.

The BAPM standards recommend that neonatal units should have three clearly defined levels of care with appropriate medical and nursing ratios. The DH review report also states that the staffing of units with enough nurses with the right skills is fundamental to service improvement in order to improve outcomes for the babies, support career development and to promote recruitment and retention. It also recommended that 75 extra cots should be established across England to meet the increased demand and indicated that an extra 200 - 300 babies lives would be saved each year. These specific recommendations give us an opportunity to monitor whether this is being achieved.

At the same time, a National Service Framework for Children, Young People and Maternity Services<sup>5</sup> standard for children using acute hospital services was published. This was followed by the balance of the NSF for Children and the Maternity Services standards<sup>6</sup> published in October 2004. Whilst all the guidance is welcome, none of the standards is enforceable.

The DH announced extra funding of £70 million over three years to achieve all of this. Significant developments are needed to achieve the improvements needed in England such as:

- establishment of neonatal networks
- neonatal transport services
- reorganisation and recruitment of staff to meet the increased establishments needed
- increased training
- data collection
- replacement and additional neonatal equipment
- improved parents overnight accommodation and facilities

However it is our view, shared by other organisations such as BAPM and NNA that this extra funding is not sufficient to achieve the step change needed to improve neonatal mortality and morbidity or the neonatal experience for both babies and their parents. BLISS recently undertook a survey *Neonatal Services – are they improving?*<sup>7</sup> to establish how the first years new money was spent. It indicated that progress has been slow and that much of the money had been used to maintain rather than develop services. We therefore need to establish what the cost is of delivering a neonatal service up to standards recommended by both BAPM and the DH. Also, a policy high on the Government's current agenda is choice for the individual to choose where to access their healthcare. What choice do babies have in their care and what choice do parents have about their baby's care and where they receive it?

#### **4. Special care for sick babies – choice or chance?**

BLISS has worked with a number of organisations and individuals to ascertain current practice and provision of neonatal care in neonatal units throughout the UK, to gather parents views of their experiences of the care of their baby(ies) and to source information to identify perinatal and infant mortality rates in the UK and throughout Europe. These organisations include the National Perinatal Epidemiology Unit (NPEU), Healthcare Decisions, the Office of National Statistics, Euronatal Study Group and PERISTAT.

Using the BLISS Baby Charter as a framework for establishing goals and benchmarks, we have attempted to identify current practice and service provision for each core value and a series of elements that contribute to achieving this and establish how this measures against what we consider sick and premature babies should be receiving. BLISS commissioned the NPEU to undertake an independent research review to identify some baseline data about current organisation and aspects of policy in neonatal care. The review included:

- a national survey of neonatal units undertaken in the winter of 2004/5
- a questionnaire sent to 220 units throughout the United Kingdom
- 153 units completing the questionnaire representing a 70% response rate (see Appendix II for breakdown of responses)
- a questionnaire for parents about their experiences was also developed which was available for on-line completion via the BLISS website for a period in Spring 2005
- 150 responses from parents representing experiences from 127 hospitals were received which were analysed by NPEU (see Appendix III for breakdown of responses)

BLISS also commissioned independent consultants Healthcare Decisions to identify the gap in staffing levels between the current levels of provision and the BAPM standards and to quantify the cost of eliminating this gap when units are working in networks.

The following report has therefore two elements:

1. current practice and provision
2. funding the future

#### **5. The BLISS Baby Charter – a benchmark for improving care**

The results from both the BLISS commissioned NPEU unit and parent surveys have been incorporated into the following Baby Charter core values.

*Every baby in the United Kingdom regardless of race, religion or culture has the right to benefit from:*

##### **5.1 Core Value 1: The same respect and dignity as adults**

Being treated as an individual and shown the same respect and dignity due to any human being responding as much to their social and emotional needs as to their medical needs.

Most of the rights included in the United Nations Convention on the Rights of the Child apply to newborn babies. Premature babies, whatever their gestation is at birth have a legal status when born. There is no doubt that everything is done for the medical and nursing care of premature and sick, newborn babies. Whilst this is vital, it is equally important to recognise the baby as an individual who can communicate its social and emotional needs and that all concerned with the baby's medical needs are also aware of their signals and work with parents to recognise and respond to them.

### 5.1.1

- By health professionals accepting and practising the values of developmental care to reduce the many stressful situations premature and sick, newborn babies face when being cared for in a neonatal unit

There is increasing recognition that the needs and development of premature and sick babies can be better addressed by focussing not just on their medical needs but also by respecting the baby as an individual who can communicate and has social and emotional needs. This move to a more baby focussed approach is called Developmental Care.

Developmental Care is an approach that uses a range of medical and nursing interventions that aim to decrease the stress of preterm neonates in neonatal intensive care. It aims to adapt behaviours and procedures in the neonatal unit to reduce the isolation, stress and emotional detachment experienced by babies receiving care in a high technology environment. These interventions are designed to allow optimal neurobehavioral development of the baby and include; awareness and control of the environment in the NICU – particularly light and sound; schedule of care giving and medical interventions; supporting and encouraging parents to be involved in the care of their baby; supporting non-nutritive sucking, positive touch and skin to skin contact by using, for example Kangaroo Care.

Study units were asked about their engagement in developmental care, whether there was a designated person or team responsible for this, what behavioural or neurodevelopmental assessments were used and what training had been undertaken. Overall 40% of units had a designated lead person or team in charge of developmental care. These leads are primarily neonatal nurses. More worrying was that only 24%, (35) had staff trained or who are in the process of receiving developmental care training.

The frequency of having a lead in developmental care and uptake in developmental care training varied across nation and unit type, further detailed in tables one and two. Half of Type 3 units have such a lead whereas only around a quarter of Type 1 was in a similar position. More English units demonstrated participation in developmental care, as denoted by having both a designated lead and more staff trained or in the process of receiving training in developmental care.

Country	Designated Developmental Care Lead	Staff Trained/ Receiving Training in Developmental Care
	% (n of units)	% (n of units)
England	41.3 (52)	26.3 (33)
Scotland	50 (6)	8.3 (1)
Wales	25 (2)	0
N. Ireland	20 (1)	20 (1)

**Table 1. Developmental Care Lead and Training by Country**

Unit Type	Designated Developmental Care Lead	Staff Trained/ Receiving Training in Developmental Care
	% (n of units)	% (n of units)
Type 1*	27.6 (8)	14.8 (4)
Type 2*	28.6 (16)	23.6 (13)
Type 3*	56.1 (37)	27.3 (18)

**Table 2. Developmental Care Lead and Training by Unit Type**

### Core Value 1: Key findings:

- 40% of neonatal units that responded had a designated lead in charge of promoting and practicing the values of developmental care. However, only 24% of units had staff that were trained or receiving training.

The types of training undertaken included NIDCAP, Brazleton, NAPI, the University of Central Lancashire Developmental Care module, NVQ level 3, infant massage and positive touch courses.

## 5.2 Core Value 2: The decisions affecting their care being made in their best interest

- Recognition that their best interest is the sole criterion for decisions regarding continuing medical care

There is continuing debate about whether babies born extremely prematurely, particularly those born at less than 25 weeks gestation, should be resuscitated at birth and whether it is fair to continue the burden of intensive care treatment on some babies.

This issue was not directly addressed in either the unit or parent survey but is an area that is of particular concern to BLISS and which we keep under review. Other countries, such as The Netherlands, have a policy of not routinely resuscitating babies born at less than 25 weeks gestation. BLISS would not support such a policy. Every baby born is an individual with individual circumstances and decisions about their continuing medical care should be made on these criteria.

Research has shown that a proportion of babies born extremely prematurely will go on to have some level of disability, in some cases severe<sup>8</sup>. It is difficult however to predict when and to whom this will happen but there is also evidence that some neurological injuries may repair themselves as the baby grows older<sup>9</sup>. The first minutes and hours of a newborn baby's life are critical, particularly if the baby is premature or sick at birth. If they are benefit from neonatal intensive care, treatment has to start immediately after birth. Delay in this can cause the baby great difficulties. We support the view therefore, that in most cases, babies should be resuscitated at birth and when treatment is needed, it should be started immediately. Decisions about continuing treatment can then be made by parents, who have been fully informed of the baby's condition and prognosis, together with the medical and nursing team that takes into account the best interests of the baby.

It is important that parents are empowered to make these difficult decisions on behalf of their baby. This empowerment can only come through frank, realistic and understandable information from those caring for their baby.

## 5.3 Core Value 3: The same level of specialist care as children and adults

The same level of specialist nursing and medical care as children and adults and be treated in the nearest specialist unit appropriate for the care they need.

### 5.3.1

- Babies needing neonatal intensive care should have 1:1 nursing as recommended by the British Association of Perinatal Medicine

Recommendations on staffing levels have changed over time. The most recent recommendations about optimal staffing levels from BAPM suggest that the following staffing levels should be regarded as the minimum standard:

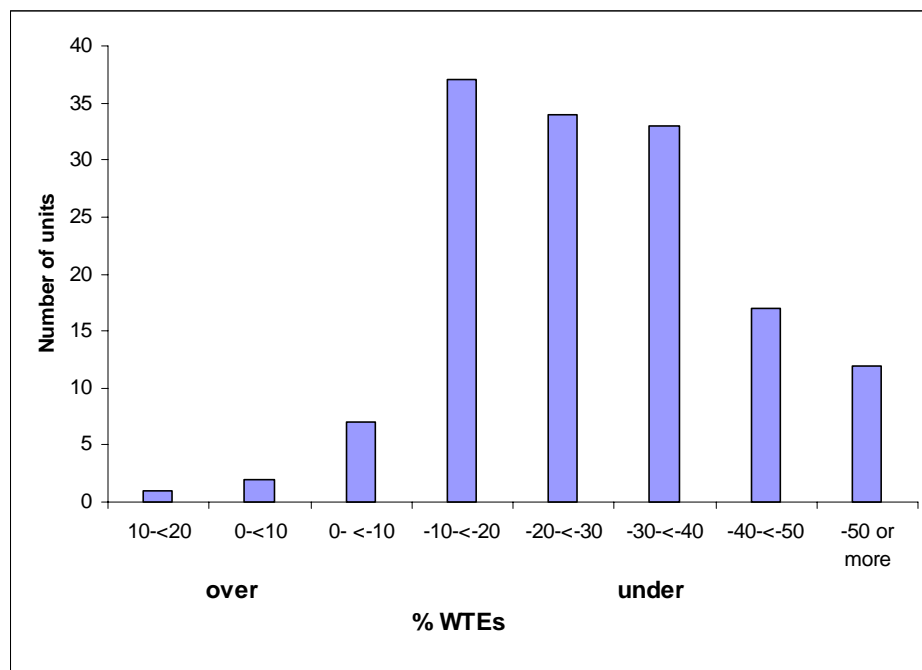
- Intensive Care: because of the complexities of care needed for a baby receiving intensive care, there should be 1:1 nursing. Occasionally when a baby is particularly unstable, 2 nurses per baby will be required
- High Dependency Care: one nurse should not have responsibility for the care of more than two babies
- Special Care: one nurse should not have responsibility for more than four babies who are receiving Special Care

A formula has been developed for calculating the number of nurses needed to provide this standard. (See Appendix IV) Using this formula the establishments required for the study units working in their current configuration were calculated for each type of unit, detailed in tables three and four. The total Whole Time Equivalent (WTE) figures are shown in table three.

Unit Type	Total Required Establishment (WTEs) (2001/2003 Recommendations)	Total Current WTE	Total mismatch (WTEs)
Type 1 (n=27)	579.31	402.57	-176.74
Type 2 (n=51)	1901.81	1253.08	-648.73
Type 3 (n=65)	4948.38	3532.18	-1450.20

**Table 3. Recommended and Current Total Nurse Establishment and Mismatch for Study Units**

As units vary substantially in size the percentage mismatch is illustrated in figure one. Most study unit establishments showed a negative value using the calculation given earlier, with only three of the 143 units (2.1%) for which data were available found to be up to or over what is recommended currently. Of note, these estimates do not take into account vacancies and the functional establishments providing the nursing element of neonatal care were thus lower than what is actually shown.



**Figure 1. Nurse Staffing Mismatch in % whole time equivalents (WTEs) for all units (n=143)**

The distribution according to unit type is shown in figure two. The extent of the current mismatch is greatest among the intermediately sized units categorised as type 2 units which provide some, though not always continuing, neonatal intensive care.



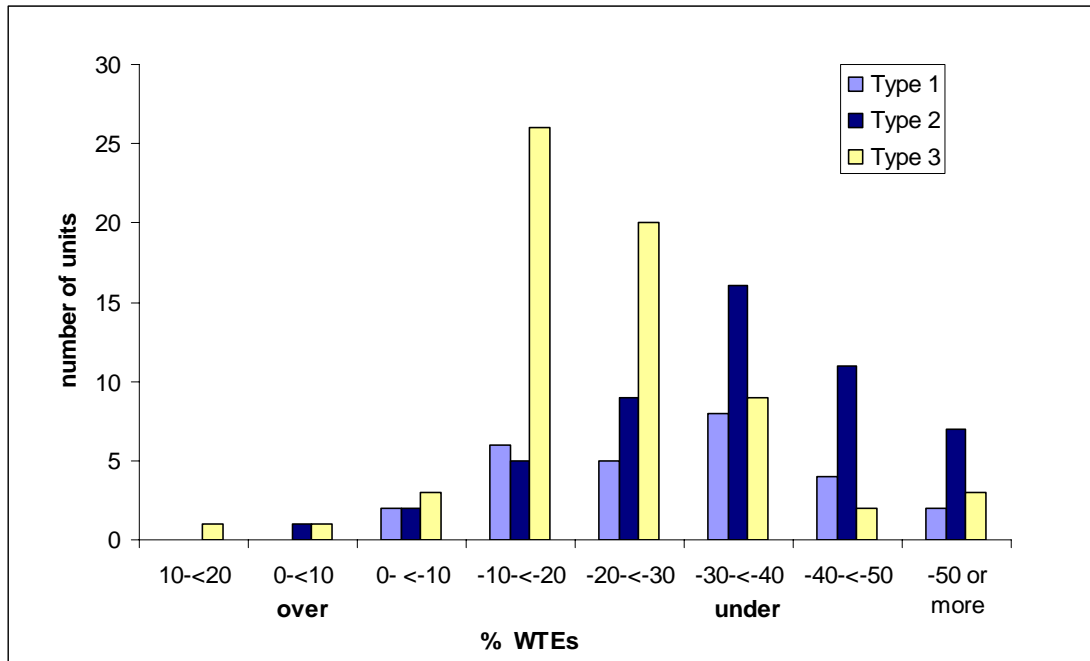


Figure 2. Nurse Staffing mismatch in % whole time equivalents (WTEs) by unit type (Type 1 n=27; Type 2 n=51; Type 3 n=65)

### 5.3.2

- There should be overnight accommodation with appropriate facilities available to parents/carers to stay with their baby particularly during intensive care

When babies are seriously ill, it is important that their parents have access to overnight accommodation preferably within the neonatal unit or nearby. This is particularly so, if the baby has been transferred to a unit a long way from home. The facilities for parents can make a difference to how welcome they feel, how much contact they have with their babies, how they and other family members, including other children, manage their visits to the unit and how easily mothers can establish and provide breast milk for their babies.

89% of units reported they had overnight accommodation for mothers on the unit, 84% could accommodate both parents whilst 40% has somewhere to stay away from the unit. However, according to the parent survey, 67% indicated there was accommodation available for mothers and 52% for both parents. This is considerably lower than the unit replies but the disparity will reflect what was vacant at the time as there are likely to more requests for accommodation than can be satisfied. Though many units have some parental accommodation, it may be limited in terms of the numbers of mothers or parents that can be accommodated at any one time.

Overnight accommodation is particularly important for parents whose babies have been transferred to another unit, usually for intensive or specialist care. In some cases this will be to a unit not far away from their home. Unfortunately, in many cases it will be to a hospital many miles from their home because their nearest unit has no available cot and is closed to new admissions. According to the parent survey, around 40% had a daily journey of up 30 miles or over to visit their baby and it cost 10% of couples £20 every time they visited their baby.

Small units may be short on space for the kind of facilities discussed above, as may much larger units caring for more babies at one time. Information was not requested about the amount of accommodation for parents which can vary a great deal. With the introduction of networks this aspect of family care needs further consideration particularly as it was also a recommendation of the DH in the neonatal review.

Study units were asked about facilities for parents and the resulting data are illustrated in figure three. It is evident that there is widespread provision of many of the facilities listed. Only 89% of units have a sitting room for parents and 80% a place to make hot and cold snacks. Playrooms for siblings are available less commonly (in 61% of units), though almost all have a toy box for visiting children (96%).

However, all the results from the parent survey about facilities for parents and families were around 10 percentage points lower than the unit replies.

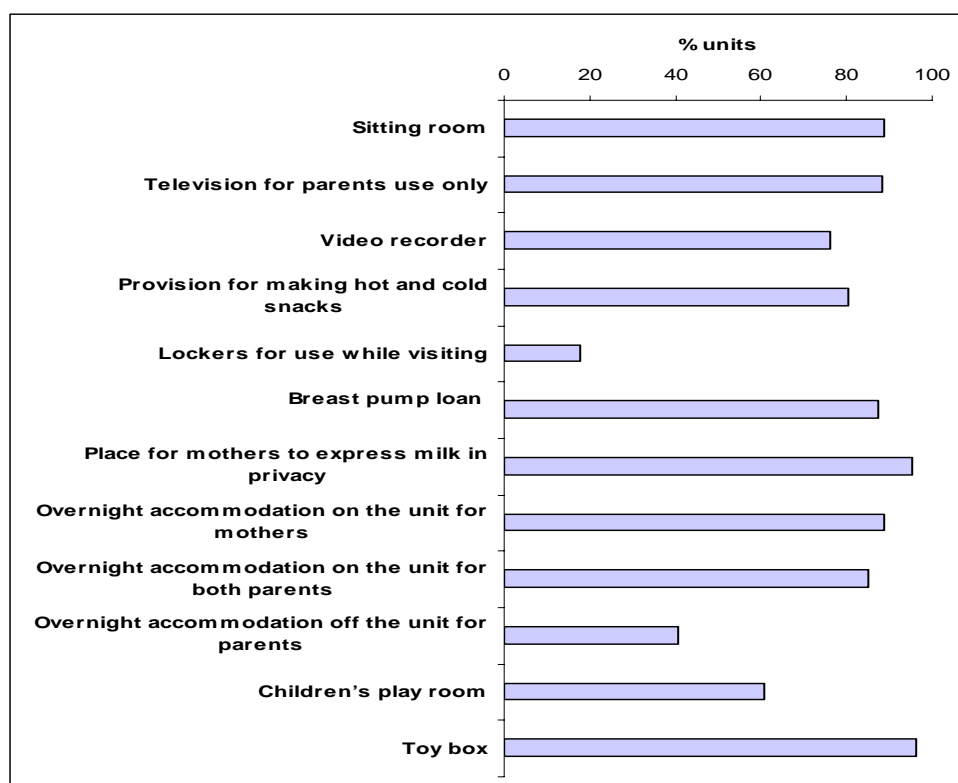


Figure 3. Facilities available for parents in the neonatal unit (153 units)

### 5.3.3

- Neonatal networks should be providing all levels of neonatal care for all their local babies within their network or as near as possible for specialist services such as surgery

As a result of the Neonatal Intensive Care Review, neonatal care is currently being reorganised into managed clinical networks. Each network will comprise of a range of neonatal units offering differing levels of care with the intention of having sufficient and appropriate capacity to care for the babies born within the network. There are three levels of units as recommended by BAPM<sup>4</sup>:

Level 1 Units provide Special Care but do not aim to provide any continuing High Dependency or Intensive Care. This term includes units with or without resident medical staff.

Level 2 Units provide High Dependency Care and some short-term Intensive Care as agreed within the network.

Level 3 Units provide the whole range of medical neonatal care but not necessarily all specialist services such as neonatal surgery.  
(Both Level 2 and 3 would also provide special care for their local babies)

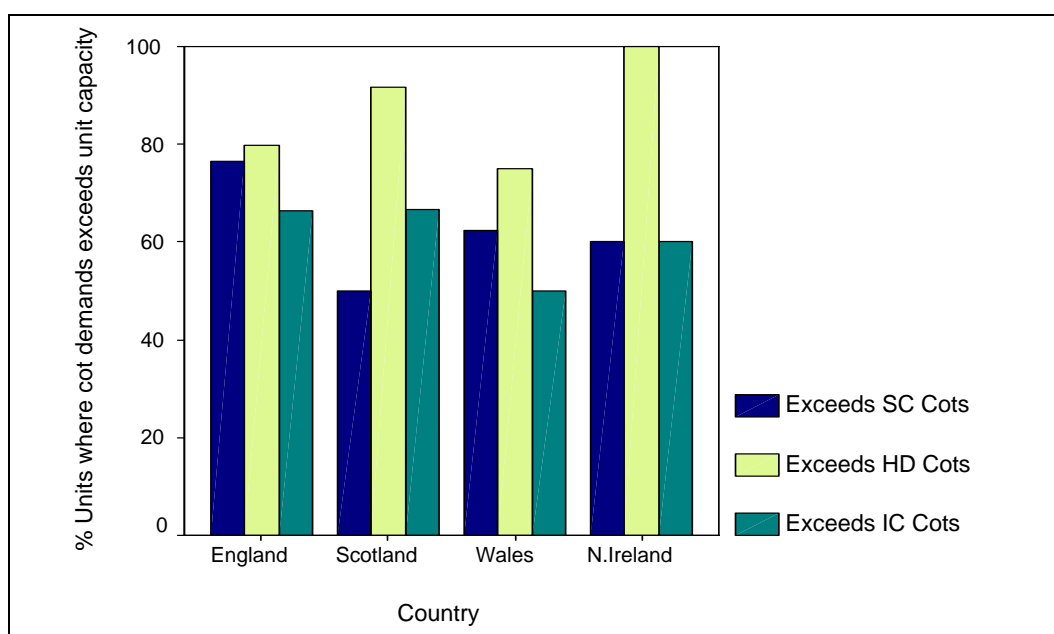
For the purposes of this project, units are described as Type 1, 2 or 3 but they map onto the levels described above. A further recommendation of BAPM 2001 is that units are so configured, resourced and staffed that they operate at 75% capacity – thus allowing for admission of new babies or return of recovering babies at all times. The development of the networks, if they are funded adequately, should result in mothers and babies no longer being transferred often hundreds of miles away because their local neonatal unit is closed to new admissions. This is often due to shortage of nursing staff or simply not enough cots.

Almost all units (95%, n=146) reported that that they exceeded their unit cot capacity. Table five details the cot demands, which exceed the unit provision for each category of cot, grouped according to unit type. Of note, 40% of type 1 units (with special care and less than 3 high dependency care cots) cared for babies requiring intensive care. Overall, high dependency care was in greatest demand with 81% units reporting "going over" on high dependency care cots.

Type of Unit	n (%) units exceeding overall cot numbers	n (%) exceeding SC Cots	n (%) exceeding HD Cots	n (%) exceeding IC Cots
Type 1	28 (93.3)	3 (76.7)	18 (60)	12 (40)
Type 2	53 (94.6)	40 (71.4)	50 (89.3)	37 (66.1)
Type 3	67 (100)	49 (73.1)	56 (83.1)	51 (76.1)

**Table 5: Cot Demands Exceeding Unit Provision by Unit Type**

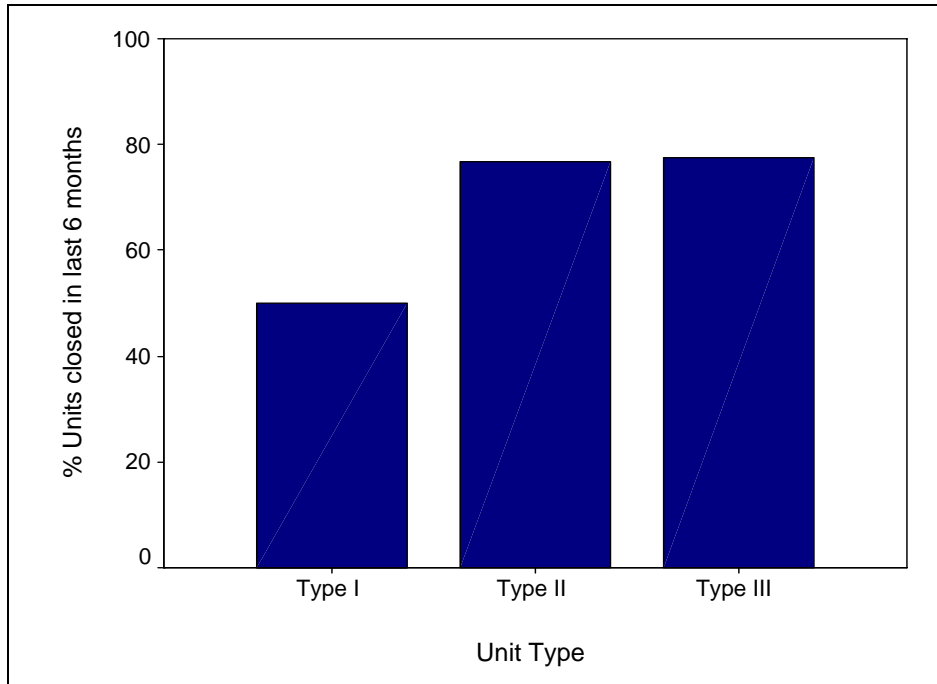
The distribution of excessive unit demands is detailed in figure four for all four nations. All the responding units in Northern Ireland reported “going over” on cot demands, versus 97.7% for those in England and 91.7% for those in Scotland. The Welsh units reported the lowest incidence of excessive cot demands at 87.5%.



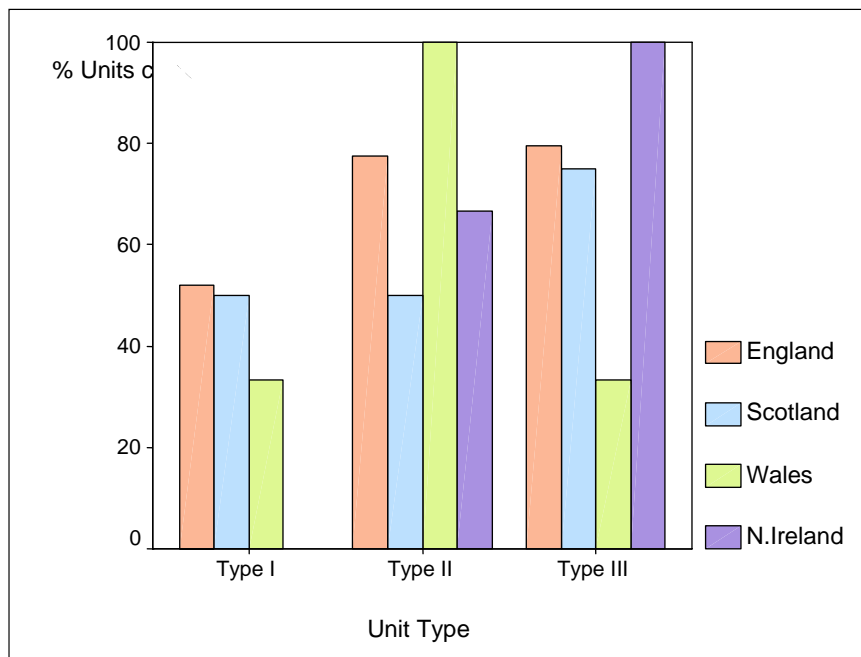
**Figure 4: Proportion of units per country where cot demands exceed unit capacity**

Currently neonatal units throughout the country find they have to close their unit to new admissions. This can be due to full occupancy or cots closed because of staff shortages. These closures lead to mothers and babies being transferred to units, often hundreds of miles away, babies from multiple births being split up and often mothers being separated from their babies. Units were asked if they had been closed to admissions. A total of 72% (n=110) of units reported that they had been closed to admissions in the previous six months. There was little difference in unit closures across each of unit types, illustrated in figure five.

However, the proportion of units closed varied according to country, with the highest closure incidence in Northern Ireland (80% of units), followed by England (73.4%, n=94), Scotland (66.7%, n=8) and Wales (50%, n=4). The breakdown of closures by unit type for each country is illustrated in figure six.



**Figure 5. Proportion of units closed to admissions in previous six months by unit type**



**Figure 6. Proportion of units in each country closed to admissions in the previous six months by unit type**

One of the factors contributing to closure of cots/units is shortage of staff against the current establishment through vacancies or absence. Units were asked about nursing vacancies amongst their current establishment.

Nurse staffing and vacancies, measured in whole time equivalents (WTEs), is shown for the study units in table six. Overall, the total number of WTEs was 5187.83 with 400.5 WTE (7.72%) vacancies. This equates to a mean nursing establishment of 36.28 WTE (4-130) with an average vacancy rate of 2.8 per unit. However, nearly a quarter of units reported having no vacancies at all. As shown, the proportion of WTE vacancies differed relatively little by unit type. Also, perhaps surprisingly, overall the current

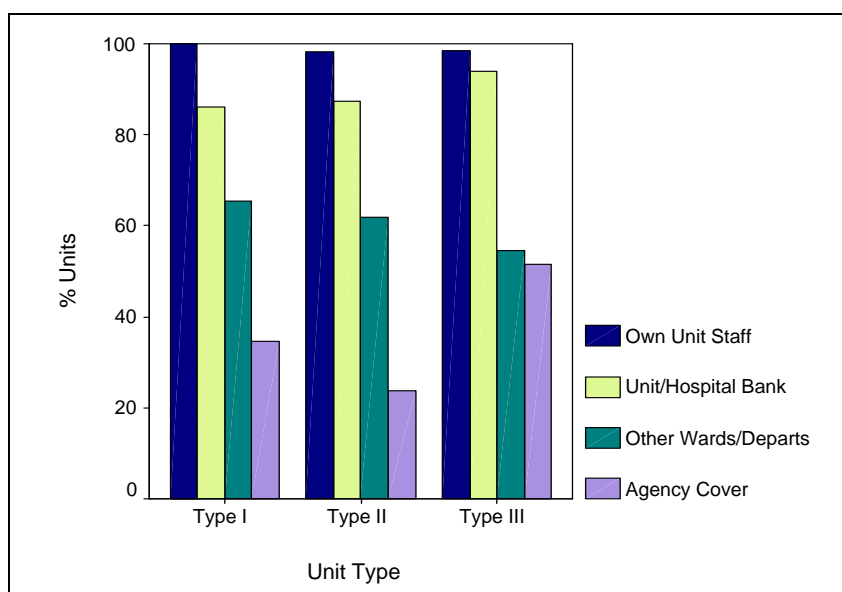
vacancy rate of 8% is no different from that reported in a large-scale study of 56 neonatal units ten years previously<sup>10</sup>.

Unit Type	WTEs			WTE Vacancies			% Vacant of Total WTEs
	Total	Mean (s.d.)	Range	Total	Mean (s.d.)	Range	
Type 1	402.6	14.91(4.32)	4-24.2	25.93	0.96 (1.28)	0-5.1	6.4
Type 2	1253.08	24.6 (8.1)	10.5-49.0	102.12	1.96 (1.76)	0-7.5	8.2
Type 3	3532.18	54.34 (23.51)	21.5-130.0	272.45	4.26 (4.07)	0-16.8	7.7

**Table 6. WTE and WTE Vacancies by Unit Type**

The highest proportion of vacancies was for staff midwives/staff nurses with 61% of all vacancies, followed by sister/charge nurses (20%).

When reviewing the neonatal nursing workforce, consideration was given to the unit policies on maintaining adequate nursing levels for the number of cots. Figure seven illustrates the use of cover for each level of unit. All types of unit primarily used their own nursing staff to cover staff shortages with agency staff being the least used by each unit type. This strategy, while least costly, is likely to contribute to further staffing difficulties. BLISS is aware of considerable anecdotal evidence of staff demoralisation and fatigue caused by increasing shortages and non-replacement of staff.



**Figure 7. Use of coverage when short staffed per unit level**

### Core Value 3 Key Findings

- Approximately 2,275 extra WTE nurses are needed in units working in their current configuration to achieve 1:1 nursing care as recommended by BAPM
- Only 2% of units for which data were available were found to reach or be near the WTE nursing establishment to meet BAPM recommendation
- The extent of the current nursing shortfall against BAPM standards is greatest amongst Type 2 units
- 89% of units had overnight accommodation for mothers and 84% for both parents. However the parents survey indicated 67% and 52% respectively. This probably relates to availability of accommodation at any one time
- 95% of units exceeded their cot capacity. 81% of Type 2 units reported exceeding capacity in high dependency cots.
- 72% of units reported they had been closed to admissions in the previous six months. There were more closures in Type 2 and Type 3 units.
- In their current configuration there is a national vacancy rate of nurses of 8%
- All types of units mostly use their own staff to cover short shortages

## 5.4 Core Value 4: The same chances as survival as babies born in similar countries and circumstances.

### 5.4.1

- By reducing perinatal and infant mortality rates in the United Kingdom

There are a number of mortality rates that are important indicators of how well we are caring for our infants; perinatal mortality indicates the number or rate of babies who are stillborn or die within the first week of life, neonatal mortality indicates the number or rate of babies who die within the first four weeks of life and infant mortality which indicates the same for the first year of life. Two in every three infant deaths in England and Wales occurred within the first 28 days of life according to the Office of National Statistics (ONS). The main causes of death were conditions related to prematurity, such as low birthweight or breathing difficulties (58 per cent) and congenital anomalies (24 per cent).

These do however, also reflect the impact that different social, age and ethnic factors have on survival. According to ONS the infant mortality rates of babies born to mothers with lower socioeconomic factors outside of marriage is ten times higher than for babies born to women with the highest socioeconomic factor<sup>11</sup>. The 2003-4 NHS Maternity Statistics showed that low birthweight babies comprised about 11% of Asian women's babies and 10% of Black women's babies compared to 7% of White women's babies<sup>12</sup>. In particular, mothers who were born in Pakistan have the highest risk of a low birthweight baby in the UK, followed by mothers born in Africa (not including East or South Africa). Whilst stature will be a contributing factor to low birthweight, it should be pointed out the corresponding infant mortality figures for these two stated groups of mothers is almost twice as high as mothers born in the UK. For example, the infant mortality rate of babies whose mothers were born in Pakistan is 10.4 compared to 5.0 if mothers were born in the UK<sup>11</sup>.

The objective of the reorganisation of neonatal care, if resourced adequately, is to result in a better standard of care and thus save 200 – 300 babies lives annually<sup>3</sup>. This should have an impact on these mortality rates towards the end of the decade.

The rates for the UK for the last three years are shown in table seven. Although it is accepted that they fluctuate, the rates shown in table seven indicate that mortality rates in all three areas increased in the UK in 2003<sup>13</sup>. Figure eight shows the perinatal mortality rate for the last five years in which it can be seen that this rate is rising<sup>14</sup>. A contributory factor to this increase is that the number of stillbirths is rising; from 5.35 per 1,000 births in 2000 to 5.77 per 1,000 births in 2003<sup>15</sup>. This increase is currently being investigated by The Confidential Enquiry into Maternal and Child Health.

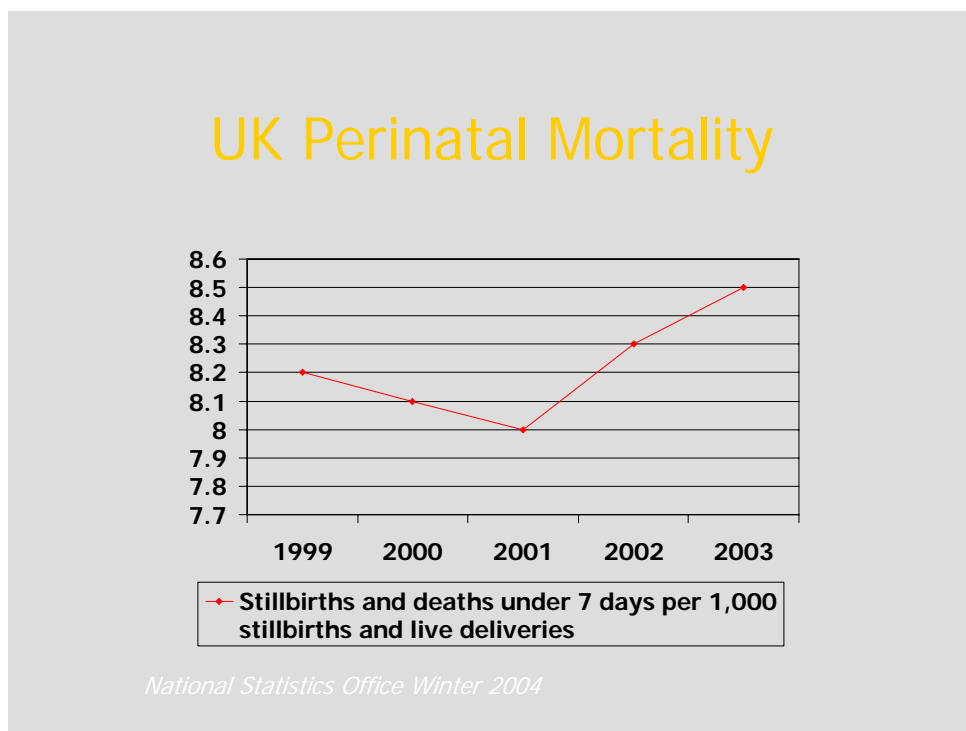
	Perinatal mortality <sup>1</sup>	Neonatal mortality <sup>2</sup>	Infant mortality <sup>3</sup>
<b>United Kingdom</b>			
2001	8.0	3.6	5.5
2002	8.3	3.5	5.2
2003	8.5	3.6	5.3
<b>England</b>			
2001	8.0	3.6	5.4
2002	8.3	3.6	5.2
2003	8.5	3.7	5.3
<b>Wales</b>			
2001	7.5	3.5	5.4
2002	7.7	3.2	4.5
2003	7.5	3.1	4.3
<b>Scotland</b>			
2001	8.5	3.8	5.5
2002	7.7	3.2	5.3
2003	8.0	3.4	5.1
<b>Nth Ireland</b>			
2001	8.5	4.5	6.1
2002	8.9	3.5	4.7
2003	8.1	4.0	5.3

<sup>1</sup> Deaths within 7 days per 1,000 live births and stillbirths

<sup>2</sup> Deaths within 28 days per 1,000 live births

<sup>3</sup> Deaths within 12 months per 1,000 live births. Source: Health Statistics Quarterly, Summer 2005, National Statistics

**Table 7. Mortality rates in UK: 2001 – 2003**



**Figure 8. UK perinatal mortality rates 1999-2003**

#### 5.4.2

- By addressing the regional differences in perinatal and infant mortality within the United Kingdom

There are wide differences in mortality rates and low birthweight between countries and regions within the UK. In 2003 Wales had the lowest national infant mortality rate at 4.3 deaths per 1,000 live births while England had the highest at 5.3. Within England, the West Midlands had the highest mortality rate at 8.6 deaths per 1,000 live births and the lowest was in the South West at 4.1 per 1,000 live births<sup>11</sup>.

Whilst these figures reflect both the population and its mix, it is necessary to ensure that the appropriate resources are in place to address the different low birthweight and premature birth rates in these different regions. A project has recently started in the West Midlands with the aim of reducing its perinatal mortality rates to nearer the national average over a five year period.

The regional mortality and low birthweight rates for England and Wales in 2003 are shown in table eight.

Region	Infant deaths by birthweight (under 1000 gms)	Infant deaths by birthweight (under 2500 gms)	Perinatal Mortality <sup>1</sup>	Infant Mortality <sup>2</sup>
North East	44	75	7.8	4.9
North West	166	282	9.0	5.9
Yorkshire and The Humber	127	222	9.0	5.7
East Midlands	117	187	9.5	5.9
West Midlands	203	320	10.2	7.4
East	111	166	7.3	4.5
London	242	360	9.5	5.4
South East	143	225	7.0	4.2
South West	92	142	7.0	4.1
Wales	55	88	7.5	4.3

<sup>1</sup> Deaths within 7 days per 1,000 live births and stillbirths    <sup>2</sup> Deaths within 12 months per 1,000 live births

Source: Childhood, infant and perinatal mortality, series DH3 no 36, National Statistics

**Table 8. Regional mortality rates in England and Wales: 2003**

However, Scotland has some of the highest perinatal rates in the UK<sup>16</sup>. Some examples are shown in table nine.

Council areas in Scotland	Perinatal Mortality <sup>1</sup>	Infant Mortality <sup>2</sup>
Clackmannanshire	15.8	10.0
E. Dunbartonshire	14.5	10.1
City of Edinburgh	11.5	5.9
Glasgow City	10.5	7.3
Inverclyde	18.7	11.1
W. Dunbartonshire	11.9	11.0

<sup>1</sup> Deaths within 7 days per 1,000 live births and stillbirths

<sup>2</sup> Deaths within 12 months per 1,000 live births

Source: General Register Office for Scotland, 2005 (provisional figures for 2004)

**Table 9. Mortality rates in selected Council areas in Scotland: 2004 (provisional)**

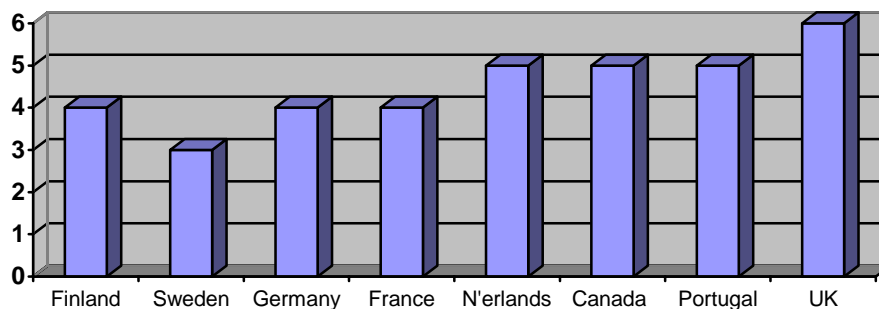
A baby born in Inverclyde in Scotland is more than two times as likely to die as a baby born in England.

### 5.4.3

- By striving for equality in perinatal and infant mortality rates with other similar countries and circumstances.

When infant mortality rates for similar countries, such as those designated by the OECD as high income countries, are compared the UK is consistently shown to have higher rates<sup>17</sup> as shown in figure nine.





**Figure 9. Infant Mortality by country 2001 (High Income OECD countries)**  
(Deaths within 12 months per 1,000 births)

Additionally, the Euronatal study published in 2003 investigated the background differences in perinatal mortality recorded between 1993 and 1998 in 10 European countries with the aim of determining the contribution of differences in care. The study found that the percentage of cases with suboptimal care factors was lowest in Finland and Sweden but highest in the UK, Greece and Portugal<sup>18</sup>.

Claims that the UK has the worst infant and perinatal mortality rates in Western Europe have been repeatedly made. It has been recognised however, that the different countries collect and collate their data using different criteria for recording births and infant deaths. Over the years, a series of studies has shown that this had led to marked differences in reported infant mortality rates throughout Europe. Consequently, the PERISTAT project funded by the European Union, has been established to identify a common set of indicators that will provide more realistic comparative ratings throughout Europe.

Even so, the Euronatal Working Group undertook a study comparing published perinatal mortality rates in Western Europe and adjusted them for common cutoff points for birthweight and gestational age. Whilst the result of this 12 country study, gave the UK an improved neonatal mortality rate over the table above, it still did not perform well against other similar European countries<sup>19</sup>.

#### Core Value 4: Key Findings

- Perinatal, neonatal and infant mortality rates rose in the UK during 2003
- Wales has the lowest national infant mortality rate at 4.3
- West Midlands has the highest infant mortality rate, at 7.4, in England
- Scotland has some of the highest perinatal and infant mortality rates in the UK, peaking with Inverclyde with an infant mortality rate of 11.1
- Even after evening out data collection differences, the UK still does badly when compared with similar countries in Europe

#### 5.5 Core Value 5: The information and support needed by parents to help them care for their baby and achieve the best quality of life

The parent survey indicated that the average duration of stay in hospital for babies in neonatal care was 56 days but this may have been distorted as a high proportion of parents surveyed had low gestation babies. However, the range was 4–140 days. This illustrates that parents or carers with a baby being cared for in a neonatal unit need a great deal of support both whilst their baby is in hospital and after discharge home. Their information and communication needs are substantial and can be addressed in a variety of ways.

A neonatal unit, particularly one providing neonatal intensive care can be a very intimidating and traumatic place for parents who are already bewildered and under great stress from having a premature or sick newborn baby. It is helpful where possible for prospective parents to have some form of introduction to the neonatal unit. This introduction can occur in a variety of ways. Parents who have previously had a baby who was cared for in a neonatal unit, women whose pregnancy may be at risk or who may have experienced an antenatal hospital stay and women and partners who only learn about the need for neonatal care in the course of delivery have different needs for information. The first group can also be divided into those who are using the same maternity and neonatal service as before and those who have moved or chosen to have the current baby in a different hospital, also with differing needs.

One way of addressing some of the parents' information needs may be to have antenatal visits to the neonatal unit, with parents able to see the facilities and to ask questions. The study respondents were thus asked about policy relating to visits to neonatal care, by groups of parents routinely in the context of antenatal care and individual visits. The responses are shown in table ten.

Seeing the unit	n (%)
AN visits to the unit	145 (94.8)
By groups of parents	81 (52.9)
By individual parents	140 (91.5)

**Table 10. Antenatal visits to the neonatal unit by parents**

Almost all units facilitated some kind of antenatal visit to the neonatal unit, most commonly by individual parents whose baby was likely to be admitted. Approximately half the study units had organised visits for women as part of antenatal education.

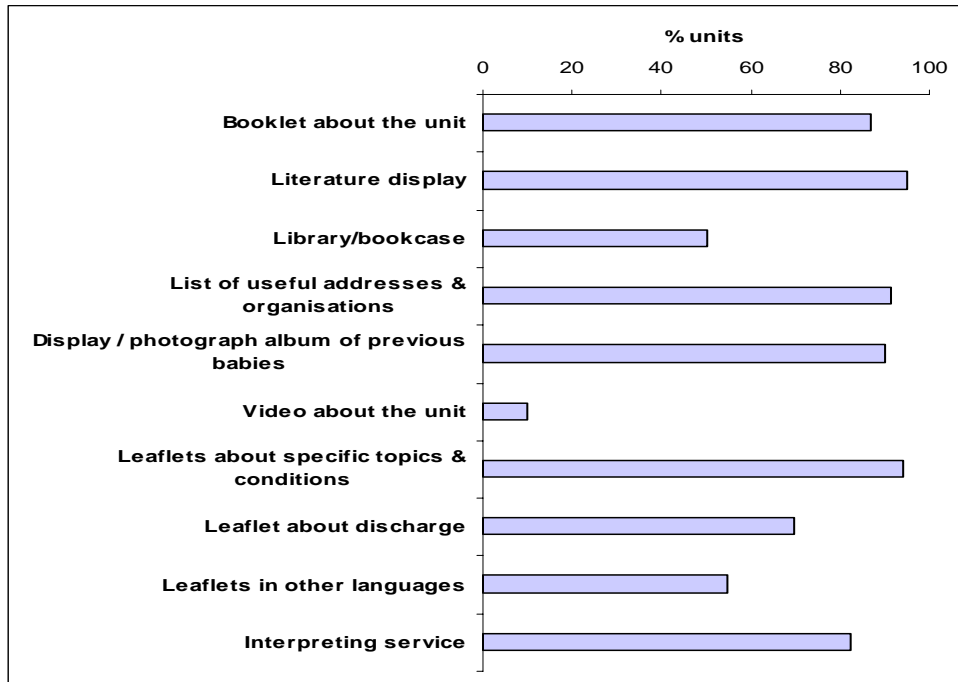
The study respondents were also asked about ward rounds and whether parents were present at this time. In a total of 84% of units parents were present for rounds (126 out of 150 units), but in most instances were only present for the examination and discussion about their baby. Confidentiality was put forward by most of the respondents indicating that selective parental presence during ward rounds was the unit policy. However, in some instances limited space and time, consultant discretion, avoidance of large teaching rounds and the intensive care area, were also put forward as a rationale for limiting the presence of parents. Of the 150 units for which data were provided, 36 (29%) parents were present without any limits. The size and design of units, some of which are very small and now quite old, make it almost impossible to have a confidential discussion at the baby's cotside.

Obviously staff themselves are important sources of information about their baby, the unit, its policies and routines, and the environment of neonatal care generally unit. As part of providing high quality care that answers the needs of parents and their babies a range of written materials and services can help in communicating with parents and families. Data were obtained about the availability of different types of information and these are illustrated in figure ten.

Almost all units reported providing written material in the form of booklets (97%) and have literature displays (95%), but this is not universal and while some use the booklets produced by, for example, BLISS, others are responsible for producing their own material. The parent survey indicated that more than 25% did not receive a booklet about the unit, nearly 20% did not receive information leaflets and only 36% were able to borrow books about preterm babies, for example. However, greater information is available in this form than was reported in a study carried out a decade earlier<sup>10</sup>.

Less common also was the availability of a video-recording about the unit, a feature that might be useful in areas where literacy levels are lower and the incidence of non-English speaking parents is higher. Just over half the study units provide information in languages other than English (55%) but only 82% reported the possibility of parents having access to an interpreting service. This is concerning when considering that Asian and Black women are at increased risk of having a low birthweight baby which is likely to need neonatal care. The 2003-4 NHS Maternity Statistics showed that low birthweight babies comprised about 11% of Asian women's babies and 10% of Black women's babies compared to 7% of White women's babies<sup>12</sup>. In particular, mothers who were born in Pakistan have the highest risk of a low birthweight baby in the UK, followed by mothers born in Africa (not including East or South Africa). Whilst stature will be a contributing factor to low birthweight, it should be pointed out the

corresponding infant mortality figures for these two stated groups of mothers is almost twice as high as mothers born in the UK<sup>11</sup>. These mothers are also likely to be recent arrivals in the UK and their language support needs will be high.



**Figure 10. Information for parents available in the neonatal unit (153 units)**

### 5.5.1

- By neonatal staff working with parents and their babies to provide skin to skin contact, positive touch and other aspects of supportive emotional and developmental care

Contact with their baby, whether it involves feeding or not is an important activity for babies and parents particularly when the baby is in the neonatal unit for some time. It is recognised that skin-to-skin contact and gentle touch can have benefits for both sides of the partnership. Skin to skin contact by using Kangaroo Care helps the parents to form an attachment with their baby, it can help stimulate or improve mother's milk production as well as having a calming effect on the baby which can help them to sleep more deeply and it has shown to improve oxygenation of the blood. Whilst babies are in a neonatal unit, they have to endure many medical procedures which cause them discomfort and stress. It is important that staff on the unit work with parents to show them how to comfort their baby through positive and gentle touch.

The study units were thus asked about practice in relation to this aspect of care. The data presented in figure eleven show that while half the units (51%) use Kangaroo Care or skin-to-skin contact and a quarter (25%) use massage or gentle touch regularly, there is a large remainder where these are occasional or absent activities.

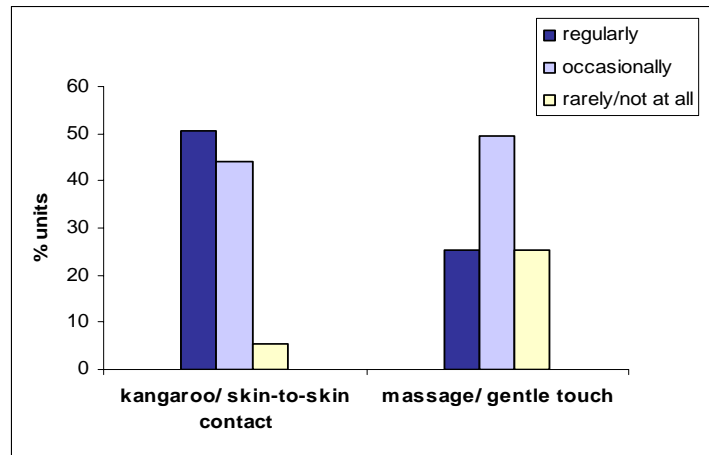


Figure 11. Use of touch and skin-to-skin contact in neonatal care (n= 151 units)

According to the parents' survey, 26% regularly had skin-to-skin contact/Kangaroo Care when they visited their baby, 50% sometimes but 24% never did.

### 5.5.2

- By neonatal staff reducing the environmental stresses faced by babies

Neonatal units can be noisy, bright and very busy places. This is not the best environment for a very sick baby, who is already under great stress and whose development and recovery can be hindered by the additional trauma of bright lights sometimes being left on all day and night, noisy people and banging of doors and cupboards.

The survey asked a range of questions about policy in relation to the quality of care and the way in which developmental needs were addressed in relation to improving the environment within the unit. The extent to which practical modifications to the general physical environment and routine are in place is illustrated in figure twelve.

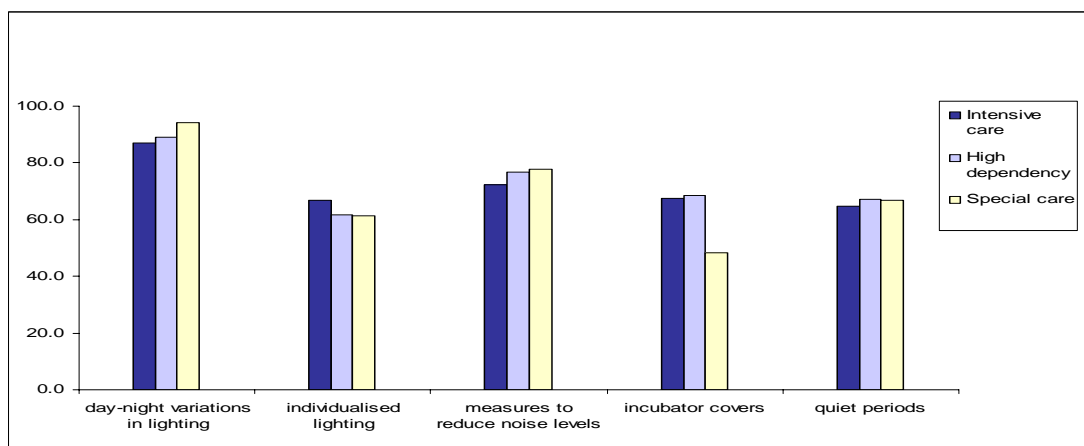


Figure 12. Aspects of environmental care used to support infants' development in different areas of care (n=145)

As far as the parents were concerned, 75% indicated that there was a quiet time in their unit and 58% used incubator covers.

Positioning for premature babies is very important whilst in the neonatal unit whether they are in an incubator or open cot. It is good to recreate the curled up position that the baby would have been in, had the pregnancy gone to full term and they also need to feel secure by having a boundary around them. These procedures can help towards the baby's physical and development needs as well reducing stress. A number of measures can be used in caring for individual babies in their open cots or

incubators which will help towards this. The degree to which these are used in the study units is illustrated in figure thirteen. All units seem to have a policy of providing some aids that will enable infants to be cared for in a space that involves boundaries created from soft and pliable materials.

72% of survey parents indicated that their baby was made comfortable by body positioning, and 85% said sheets were formed into a nest.

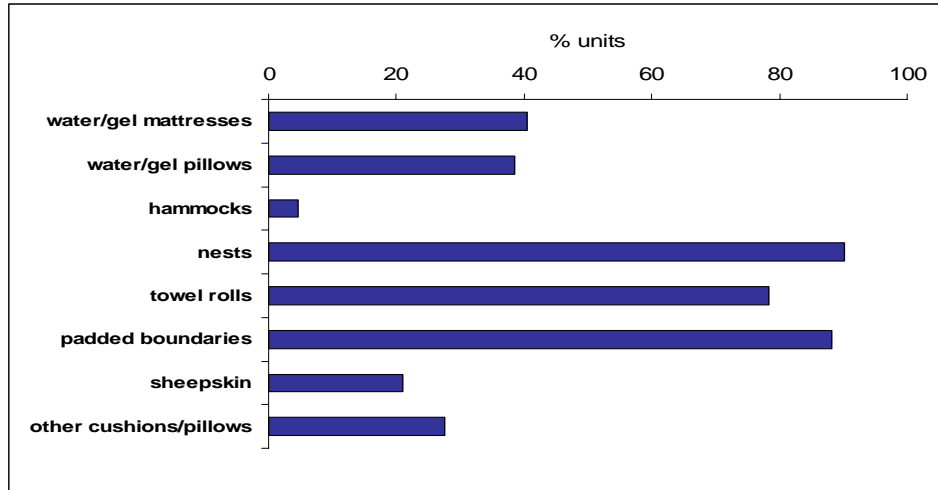


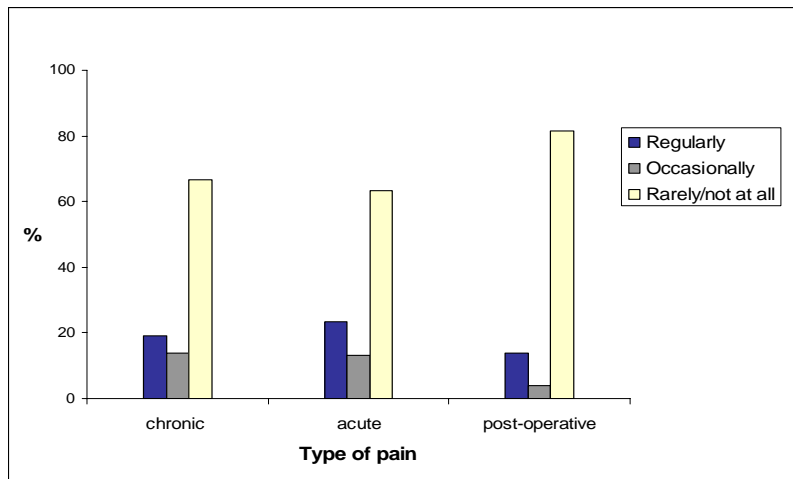
Figure 13. Aids used to maintain babies' positioning in neonatal care

### 5.5.3

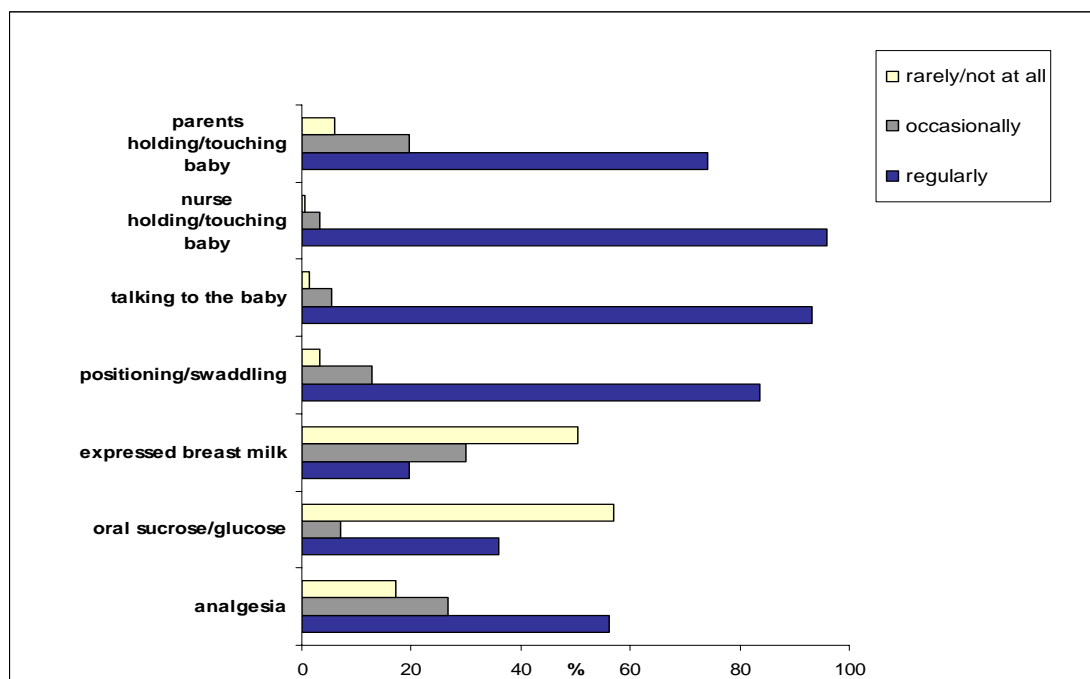
- By the neonatal team paying more attention to pain relief and working with parents/carers to help comfort their baby during painful procedures

It is now recognised that preterm and newborn infants experience pain in the course of procedures and handling and that this may affect them in a number of ways<sup>20-22</sup>. The extent to which pain scales are in use in neonatal care and the procedures used with a baby before or during a painful procedure are shown in figures sixteen and seventeen. It seems that pain scales which can be used for systematically assessing this aspect of care and an infant's responsiveness appear to be used relatively little. The survey indicated that that only 20% of units are regularly using a tool to assess chronic, acute and post-operative pain.

A number of methods are used to provide pain relief, including analgesia administered via different routes, depending on the procedure. The use of tactile measures to comfort infants such as gentle touch and positioning, giving breast milk or a dummy/comforter is relatively common, though oral sucrose/glucose is used less frequently. This may increase, as indicated by open-ended comments from respondents relating to the development of new protocols in this area. Parents were asked about ways their baby was made comfortable. 48% indicated that their babies were given pain relieving drugs and only 38% reported that massage/stroking techniques were used.



**Figure 14. Use of a pain scale for chronic and acute pain in neonatal care units) and post-operative pain (102 units) (n=150)**



**Figure 15. Measures used with babies during a painful procedure in units (n=144)**

#### 5.5.4

- By involving parents so that they recognise their baby's signals and what their baby is communicating and to develop a relationship with their baby.

Premature babies, though less mature than full term babies, are still sensitive to a wide range of stimuli. It is important that staff and parents understand baby's body language and reactions. Unit staff can work with parents to recognise when and what baby is communicating, for example, feeling comfortable or perhaps more importantly, uncomfortable.

The care team should show parents how to hold and comfort their baby during treatments and procedures, how to maintain their natural curled up position, make a 'nest' which supports baby and provides some boundaries.

In the parent survey, 85% of units used sheets rolled into a nest and 72% practiced body positioning.

#### Core Value 5: Key Findings

- 29% of units had no limits about the presence of parents in the neonatal unit
- 25% of parents surveyed reported that they did not receive an information booklet about the neonatal unit and nearly 20% reported they did not receive general information leaflets
- Nearly 20% of units reported that they did not have access to an interpreting service
- Half the units surveyed use skin-to-skin contact (Kangaroo Care) and only a quarter use massage/gentle touch regularly. According to the parents survey only 26% regularly have skin-to-skin contact, 50% sometimes but 24% never
- 75% of both units and parents indicated a 'quiet time' took place during the day but only 58% of parents reported the use of incubator covers
- The use of a pain scale is only used by around 20% of units for chronic, acute and postoperative pain
- Less than 60% of units regularly use analgesia for pain relief. The most regularly used measures for comforting babies during painful procedures are gentle touch/holding, talking to baby and swaddling.

#### 5.6 Core Value 6: The opportunity to have the benefit of their mother's breast milk when appropriate and the maximum support for their mother to provide breast milk and to breastfeed.

The benefits of breastfeeding are well known but for premature babies having mother's breast milk is particularly important. These babies are especially vulnerable to infection as being born prematurely has interrupted the transfer of their mother's protective antibodies. Breast milk provides these valuable antibodies as well as nutrients, growth factors and hormones.

Mothers of premature or very sick babies need encouragement and support to establish breastfeeding. If the baby is very premature it will not be strong enough or be in a position to suck, and mothers will need to establish their milk supply by expressing and feeding their babies by tube and then progress on to breastfeeding. This may be even more difficult by the mother having been discharged from hospital and separated from her baby. Additionally, the process whereby hormones responsible for stimulating milk production during the later stages of pregnancy may have been cut short. Specialist breastfeeding support is important, as well as taking into account the mother's cultural or religious beliefs.

##### 5.6.1

- By the provision of specialist breastfeeding counsellors

Units were asked if they had a breast feeding advisor. Only 29 per cent of respondents indicated they had. When broken down into types of units, it was as follows:

Type 1 Unit:	14%
Type 2 Unit:	28%
Type 3 Unit:	36%

A quarter of the parents surveyed were not satisfied with the advice, help and support given to them about breastfeeding.

##### 5.6.2

- By providing comfortable surroundings for expressing breast milk or breastfeeding which also respect mother's personal or religious need for privacy

Units were asked about facilities for supporting mothers to provide breast milk. 95% indicated that there was a place for mothers to express breast milk in privacy and 80% had breast pumps for loan.

However, 36% of parents did not feel they had enough privacy for breastfeeding. Also, 25% of mothers who were bottle-feeding felt they didn't have enough privacy.

#### Core Value 6: Key Findings

- Only 29% of neonatal units reported having a specialist breastfeeding counsellor. The lowest indicated was 14% of Type 1 units
- A quarter of the parents surveyed were not satisfied with the advice, help and support received.
- 95% of units indicated there was a place for expressing breast milk in privacy. However, 36% of parents did not feel they had enough privacy for breastfeeding.

### 5.7 Core Value 7: The necessary follow-up care and support after going home to achieve the best chance for a healthy future.

#### 5.7.1

- On discharge from hospital, there should be a care plan for the baby's specific needs agreed by the community health professionals and the parents/carers.

Discharge from the neonatal unit is a significant milestone for most parents of babies who were sick or born preterm. The study units were asked about whether there are criteria for discharge of babies from the neonatal unit and about where follow-up takes place. 60% of units reported they had a specific criteria for discharge home. Details of their responses are shown in table eleven.

	n (%)units
Specific criteria for discharge home	89 (59.33)
Community follow-up	115 (76.67)
Community follow-up that is unit based	71 (47.3)

**Table 11. Discharge Procedures (n=150 units)**

Some of the criteria for discharge provided by the study units appear more prescriptive than others, with some relating to a weight or gestational age cut-off. However, generally if a baby is maintaining body temperature, growing and feeding well orally and parents are thought to be able to cope, then discharge is seen as appropriate. The emphasis in most of the responses was about taking an individualised approach and recognising the more complex needs of some babies in relation to planning discharge.

Less than a half had community follow-up that was unit based.

#### 5.7.2

- Parents and carers should receive, or have access to, support and information about their baby and their care

This particular issue was not particularly addressed in either of the surveys. However, parents and carers can feel very isolated and lacking in confidence about caring for their baby when they are discharged from hospital. Studies have shown that parental stress and stress levels are higher and



depression is not uncommon<sup>23</sup>. Although hospitals seek to discharge babies home earlier many may have been in neonatal care for some time; the average length of time for baby's stay from the parent survey was 56 days but it ranged from 4-140 days. Parents and families will have grown used to receiving a high level of support in the neonatal unit and having health professionals around to answer questions. Once a baby is home continuing support from community health professionals for the family is essential, as the daily routine for a premature or sick baby may well be more challenging and stressful for the parents and there are many development issues about which they will want advice.

In 2004, BLISS launched the Community Practitioners Information Guide<sup>24</sup> and Programme. This was in response to an identified need, both as a result of comments from parents and discussions with relevant organisations, for more information for community health professionals about the care of babies in the community following discharge from the neonatal unit. The information needs at this time are reflected in majority of calls to the BLISS telephone support line being from parents after their baby has been discharged home. Particular areas of concern are feeding/weaning issues, development and behavioural problems, caring for baby at home and information about local support services.

There is little concentration in the training curriculum of community health professionals, in particular Health Visitors who would visit the baby and parents when first home, about the care of the graduate premature baby and the support of parents. This needs addressing.

### 5.7.3

- Babies should have access to the specialist treatment, care and support necessary for the best quality of life possible

Many premature and sick, newborn babies have on-going medical conditions when at home, for example, those discharged still on oxygen therapy or still on tube feeds. Some will continue to have chronic conditions throughout their childhood. Other babies will be discharged with known disabilities such as visual or hearing impairment and a number will go on up to develop more serious disabilities which need ongoing medical and social support. Plans for follow-up and who has medical and social responsibility for the management of these infants should be identified.

Social factors play a major part in putting some mothers at risk of having a premature or low birth weight babies. Some families are more vulnerable than others and they may need extra help and support.

Postings on the BLISS parents' message board illustrate that many parents are not clear where to go to for advice or clarification as their babies grow up and still feel isolated.

Only 75% of surveyed units indicated that there was community based neonatal follow up for babies after discharge. Better follow-up of these babies and a long term care plan would contribute to better outcomes and improved quality of life for both the child and the parents.

#### Key Findings

- 60% of units reported they had a specific criteria for discharge home
- There is little concentration in the training curriculum of community health professionals, in particular Health Visitors who would visit the baby and parents when first home, about the care of the graduate prem and the support of parents
- Only 75% of surveyed units indicated that there was community based neonatal follow-up for babies after discharge
- BLISS receives most calls to its Telephone Helpline from parents when their baby has been discharged home

## Conclusion

This first *Special care for sick babies – choice or chance?* report has highlighted a number of key areas of concern in the care of babies needing neonatal care when comparing the findings of two surveys and other information sources against our Baby Charter core values and the gap analysis undertaken.

More and more babies born prematurely or sick are surviving in the UK and this is down to the increased knowledge and dedication of the medical and nursing care they receive. Neonatal networks will go some way to improving the provision of the service but this report indicates that there are many areas of concern. More attention needs to be focussed on the individual needs of the baby. Parents, irrespective of their race, religion, culture or social class need continuing support whilst their baby in the unit and at home. Finally, if we are to reduce infant mortality, the serious shortfall in the number of nurses both in terms of increasing establishment and recruitment to the available workforce, as well as funding needed to be addressed.

It is now up to neonatal units, neonatal networks, commissioners, the Government and professional organisations to support the BLISS Baby Charter and strive to achieve its core values.

## 7. Funding the future

The first part of this report has dealt very much with how services are provided currently. Reference has been made to the reorganisation of neonatal services into managed clinical networks, particularly in England. These neonatal networks are now being developed and this development is in very different stages throughout the country. It is hoped that service provision will look very different over the next few years and that the nursing and medical staffing needs will be adjusted to suit the different levels of units operating within each network and the configuration of the network.

The report has already referred on page 16 to the increased number of nurses needed to achieve the BAPM standards in each level of unit and what the current shortfall is against the recommended standard. This calculation has been made based on the units working at their current type or level and not necessarily in a formal network.

However, it is important to look at the gap in staffing levels between current and BAPM standards in neonatal intensive care provision in England when working as a network and the cost of eliminating that gap.

BLISS commissioned Healthcare Decisions, a company experienced in providing consultancy advice to commissioners and providers setting up neonatal networks to investigate this. This project was undertaken at the same time as the NPEU study reported in the preceding sections. Healthcare Decisions did not therefore have access to this new data.

### 7.1 Objectives of the funding the future project

The objective of this project is to identify and quantify the gap in staffing levels between the current levels of provision and those set out in the BAPM standards and to estimate the cost of eliminating this gap. Specifically the project focuses on identifying the following:

- Current nurse and doctor staffing levels for neonatal intensive care in England
- Staffing requirements to satisfy BAPM standards based on existing configuration
- Staffing requirements to satisfy BAPM standards based on 'typical' network configuration
- Quantify the gap in current and BAPM staffing levels for the above
- Quantify the cost of eliminating the gap between current staffing levels and BAPM guidelines when working in a network configuration

### 7.2 Approach to estimating current provision

The first stage of the analysis was undertaken using data provided by the NPEU gathered from their survey of neonatal intensive care, the *Neonatal Resource Study* carried out in 2002/3<sup>25</sup>. This allowed the

identification of current staffing levels based on a survey of all 190 units in England. The survey achieved a 45% response rate, of which 58 units proved to have sufficient data for the purposes of this analysis, giving a 30% sample.

Key information was drawn from the survey data and this is presented in Table 12 below. This details the staffing levels for neonatal units based on a sub-sample of 58 units and all figures refer to whole time equivalents (WTEs) so are not based on headcount, rather capacity.

NPEU analysis	Medical Staffing (WTE)			Nurse Staffing (WTE)			
	Consultants	Middle	SHO	ICU Nurses	HDU Nurses	SCBU Nurses	Total
Situation 2002/3	125	141	309	823	1047	310	<b>2,180</b>

**Table 12. Analysis of Staffing Levels in NPEU sampled Units**

The NPEU data identified the number of nurses available by grade in each unit. Based on this information and using a formula (see Appendix IV) for distributing the nurses between ICU, HDU and SCBU (identified through previous work) it was possible to apportion the existing nursing staff numbers between the three levels of care.

On the basis of these data, an extrapolation for the whole of England was made. There were two ways of doing this; either based on the number of births covered by the units in the sample as a proportion of the total, or based on the number of units as a proportion of the total number of neonatal units in England. This assumes that the sub-sample of 58 hospitals provided by NPEU data is representative of the rest of the neonatal units in England; there is no reason to believe this is not the case; it is more than reasonable to assume that a 30% sample would not be biased. Although one could argue that those units who thought that they were well-staffed might be more likely to respond, one could also equally argue that those who felt they were under-staffed might be more likely to respond if they thought it might secure additional resources for neonatal care. It has been assumed that these two factors would balance and eliminate any potential bias.

Both approaches were undertaken to ensure consistency and found that they both provided almost identical results. For the purposes of this analysis the first approach was undertaken.

The results of the extrapolation are presented in table thirteen below:

TOTAL extrapolated to England	Medical Staffing (WTE)			Nurse Staffing (WTE)			
	Consultants	Middle	SHO	ICU Nurses	HDU Nurses	SCU Nurses	Total
Situation 2002/3	423	476	1,048	2,791	3,550	1,049	7,390

**Table 13. Analysis of Staffing Levels in England**

### 7.3 Approach to estimating BAPM compliance

The second stage of the analysis required an estimate of the staffing levels required to satisfy the standards set out by BAPM guidelines using an agreed formula (Appendix IV).

On this basis, depending on the level at which the unit operates and the number of cots in each unit it is possible to calculate precisely the doctor and nurse number required to satisfy BAPM standards.

The estimation of the level at which each unit operates and the number of cots required by each unit depends on three main factors:

- The number of births and babies requiring intensive care for each level
- The extent to which hospitals attempt to treat all the demand in their area
- The extent to which hospitals network and centralise specialist facilities

The estimates in this analysis were based on the following key data:

- The number of births and neonatal activity were based on activity data from 2003 for hospitals in a sub-sample of 45 hospitals extrapolated to the whole of England using the same method as above.
- Assuming hospitals treat all (calculated at 95%) of their demand in their own facilities or network.
- Assuming supporting hospitals provide 48hr stabilisation of very sick babies before transfer.
- Assuming three network scenarios;
  - no networking (ie hospitals providing all levels of care)
  - networking at a ratio of three to one (3:1) – that being three hospitals working together with one of them acting as a level 3 unit, and all of them providing level 1 and 2 care.
  - networking at a ratio of five to one (5:1) – that being five hospitals working together with one of them acting as a level 3 unit, and all of them providing level 1 and 2 care.

All the subsequent calculations used the Neonatal Intensive Care Capacity Planning Toolkit as developed by the DH with Healthcare Decisions and used by Strategic Health Authorities to plan neonatal services. This ensures our modelling:

1. takes into account variable arrivals and variable length of stays
2. calculates the staff requirements based on the BAPM standards

By modelling both aspects BAPM compliance is ensured but also that there is sufficient neonatal capacity (cots and staff) in England. This is achieved without the side effect of unplanned transfers of babies.

The assumptions above are key to the extent of the estimated gap between current and BAPM provision and are based on our experience of what networks could look like as they are developed over time. There are issues of where hospitals currently are in terms of networking development that will be discussed further when the results of the gap analysis are presented.

The estimated staffing levels to achieve BAPM compliance for the three scenarios above are presented in table fourteen below.

Network toolkit analysis	Medical Staffing (WTE)			Nurse Staffing (WTE)			
	Consultants	Middle	SHO	ICU Nurses	HDU Nurses	SCBU Nurses	Total
No network	1,375	1,571	1,571	3,839	3,074	3,168	10,080
3 to 1 ratio	641	707	1,073	3,839	3,061	3,174	10,074
5 to 1 ratio	495	552	977	3,814	3,061	3,174	10,049

**Table 14. Analysis of Staffing Levels required in England to meet BAPM at different Networking**

## Ratios

### 7.4 Gap Analysis Results

The estimates presented in the previous section form the core data for the gap analysis.

The gap analysis is presented in two stages:

- Estimating the gap between current staffing levels and BAPM standards for doctor and nurses
- Estimate the cost of eliminating this gap

#### 7.4.1 Estimating the staffing gap

The first estimate takes the results of the analysis above and identifies the gap based on the three scenarios: no network, 3:1 and 5:1 ratios as presented earlier.

The estimated gap for each of the doctor categories is presented in table fifteen and figure sixteen below.

Gap Analysis	Medical Staffing (WTE)		
	Consultants	Middle	SHO
Current vs No network	952	1,094	523
Current vs 3 to 1 ratio	219	230	25
Current vs 5 to 1 ratio	72	75	-71

**Table 15. Medical Staffing Gap**

The figure indicates that there appears to be a significant gap between the estimated current number of staff and the estimated required number to satisfy BAPM standards. However, this gap is differentially distributed and for doctors' numbers depends crucially on the extent of networking and also varies significantly between grades. For the three grades identified by BAPM it is apparent that, if hospitals do not operate in networks but attempt to provide all levels of care themselves for all their population catchments, then there appears to be a significant gap between current and required doctor numbers. It is estimated that the number of consultants would have to grow by over 200% to eliminate this gap (the gap is not much better for middle grade at 230% although it is better for SHOs at around 50% growth)

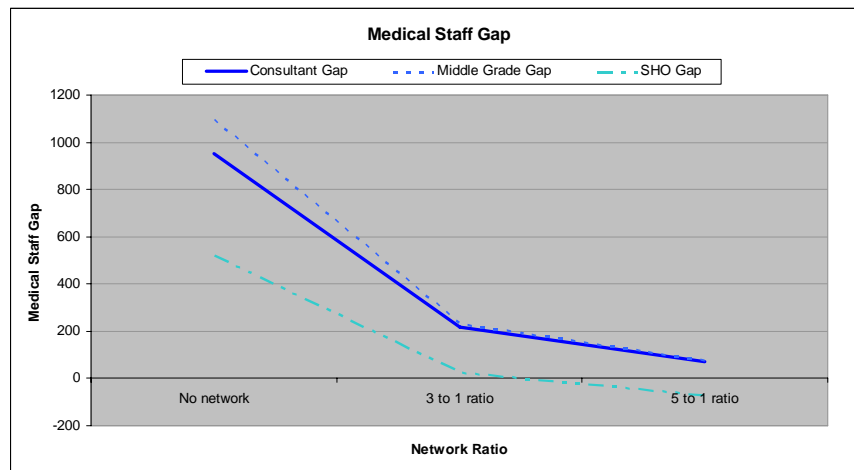


Figure 16 shows how the gap between the current levels of doctors' numbers and the BAPM standards narrow significantly as hospitals network more intensively.

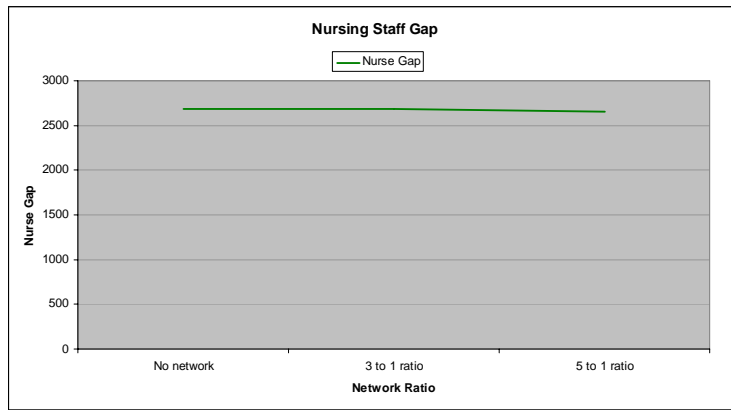
**Figure 16**

However, it is equally apparent, as hospitals network more and share scarce staff across geographic and population bases the gap narrows substantially. In fact, if hospitals networked at a ratio of 5 to 1 for intensive care (centralising their level 3 care), then the gap in consultant and middle grades reduces to a required growth of just over 15% in workforce, and it is estimated that there would be adequate SHO numbers to achieve BAPM standards at this level of networking. This can be seen clearly in figure sixteen above.

The estimated gap for each of the nurse categories is presented in table sixteen and figure seventeen below.

Gap Analysis	Total Nurse Staffing (WTE)
Current vs No network	2690
Current vs 3 to 1 ratio	2684
Current vs 5 to 1 ratio	2659

**Table 16. Nurse Staffing Gap**



**Figure 17**

The estimated gap between BAPM standards and current provision for nurses suggests that around 2,700 more nurses are needed in neonatal intensive care to meet BAPM standards. These do not vary based on the extent of networks as they are not as dependent on the level of care, as are doctor numbers, but rather on the number of babies requiring care (which does not vary).

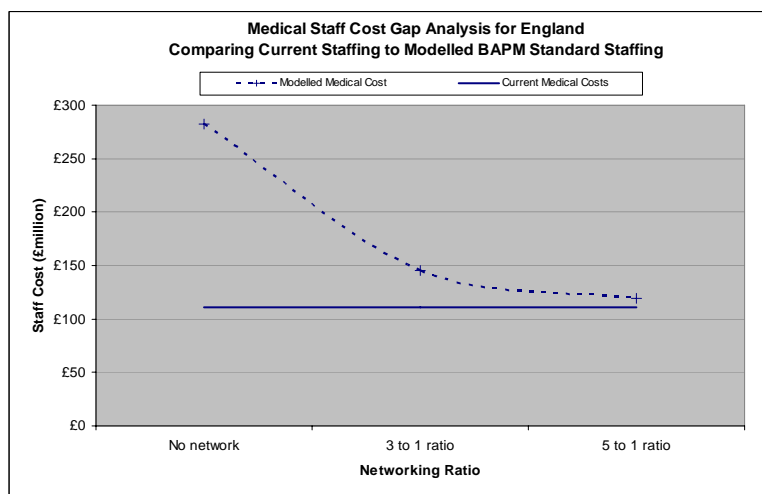
It is estimated that in order to close the gap between current and required nurse numbers the total nurse workforce must increase by over 25%. However, from the analysis, and based on the formulas identified earlier, it appears that the entire shortfall in nursing is in grades C and below; those needed for SCBU work. If the gap in nurse numbers is primarily in the lower grades, then this gap may prove easier to close as the lead time in terms of recruitment and training is likely to be less than for more experienced higher grade specialist nurses.

NB. It should be noted that prior to managed clinical neonatal networks (currently at various stages of planning and implementation around England) a limited number of units already networked on an informal basis. This means that to assume 'no networking' is very much a 'worst case'.

### 7.4.2 Estimating the cost of eliminating the staffing gap

The final stage of the analysis is to estimate the cost of eliminating the staffing gap identified above. To undertake this analysis requires converting the staff numbers into unit costs and aggregating these on the basis of the doctors and nurse numbers. The basis for the staffing costs were taken from 'Unit Costs of Health and Social Care' (Netten et al 2004). All costs are presented in 2004/5 prices. (Appendix V)

The annual cost of eliminating the gap between current and BAPM standards of provision is, as above, very much dependent on the level of networking, at least for the doctors. Again, the results are presented in terms of the extent of networking. As can be seen in Figure eighteen, the cost of eliminating the gap differs widely depending on the extent of networking.



**Figure 18. Cost Gap Analysis for Medical Staff**

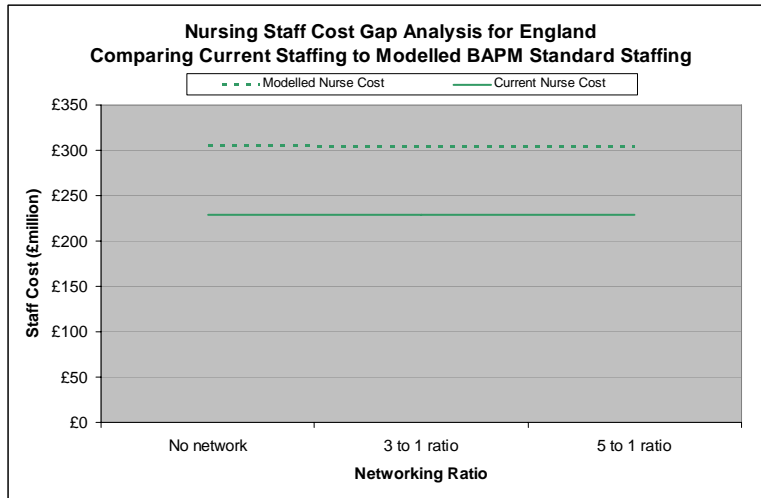


Figure 19. Cost Gap Analysis for Nursing Staff

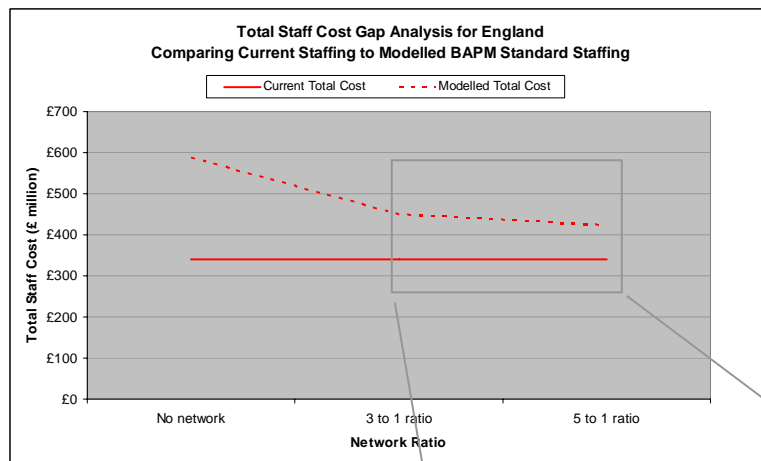
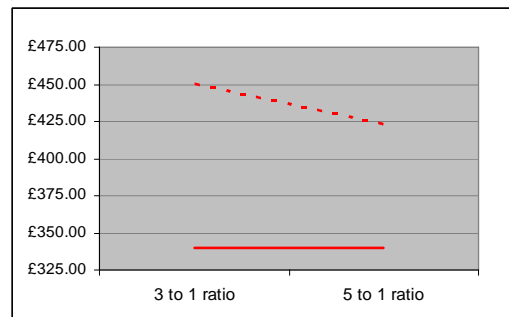


Figure 20. Cost Gap Analysis for Medical and Nursing Staff



Gap Analysis	Wage Cost (£m)		
	Medical Cost	Nurse Cost	Total Cost
Current vs No network	£171	£76	£247
Current vs 3 to 1 ratio	£34	£76	£110
Current vs 5 to 1 ratio	£8	£75	£83

**Table 17. Wage Cost Gap for England**

If hospitals do not network at all then the cost of eliminating the gap in staffing requirements is estimated to be around £250m. However, if hospitals do network effectively, it can be reduced substantially but still stands at over £80m per year. However, it should be noted that this cost, if hospitals network, is primarily due to the additional nurses required and can all but be eliminated for doctors.

Note that the analysis in this document has a confidence estimate of plus or minus 5%.

## 7.5 Conclusions and discussion for the future

It is clear from the analysis above that there remains a substantial gap between current staffing levels and those required to satisfy the BAPM standards and that this gap would cost a significant amount each year to close. There is, however, better news if hospitals network, as the gap, particularly for doctors numbers, crucially depends on the extent to which hospitals share their scarce resources. If hospitals engage in fairly intensive networking, ie a ratio of 5:1, then the gap in doctor's numbers between BAPM standards and current provision can almost be eliminated. This has clear benefits in terms of costs and also outcomes for babies.

The picture appears less rosy for nurse numbers, where these are far less dependent on the extent of networking, and the gap remains, regardless of networks, at around 2,700 nurses at a cost of £75m per annum. The issue here may not only be finding the money but also about finding the nurses. Whilst the analysis indicates a shortfall in the total number of nurses, this appears to be unevenly distributed between the different grades and consequently the different levels of care. There appears, from the results, to be sufficient numbers of nurses in ICU and HDU, with the shortfall mainly appearing for lower grade SCBU nurses. This may not tally with anecdotal experience and may have a number of explanations:

- The analysis undertaken here is at a strategic level and as such estimates the *total aggregate* number and therefore does not take account of regional variations. In some regions there may well be a shortfall of ICU and HDU nurses.
- As with cots, there may be sufficient numbers in aggregate but these may not be appropriately distributed around the system at present. This may be a significant hurdle to overcome if nurses are not geographically mobile.
- The actual situation may also be more complicated as nurses in higher grades may be able to flex downwards to provide support and cover for lower grade nurses in the HDU & SCBU when needed. However, we adjusted our algorithms downwards to ensure that we did not over-allocate to the higher levels of care. The results of the analysis still indicated that there was sufficient provision of ICU nurses and that the shortfall appeared to be for SCBU nurses.

Perhaps one encouraging note here is that if the shortfall is indeed for lower grade nurses, it is likely that the training period for these nurses is shorter and thus it may be possible to fill the gap sooner than if the gap was for more experienced higher grade nurses. However, there needs to be more training places for those who want to pursue this area of nursing.

Networking can help to eliminate the gap and move towards BAPM standards which results in lower cost and better outcomes, supporting the National Service Framework and the Department of Health's current policy direction, but a note of caution needs to be exercised here. For networking to be truly effective there needs to be appropriate facilities and organisation in place for transferring the sickest babies to the more centralised facilities (costs which are not included in the analysis) and, perhaps more crucially, a significant change of culture within neonatal intensive care units providing care.

The question as to whether a 5:1 network ratio is practical is dependant on a number of local issues. There is no doubt that this degree of networking is achievable and some networks in the South East of



England have already been created with this ratio. However other factors do have an influence, such as: the physical size of the level 3 unit, how dispersed the units are and the local geography, how good the public transport system is between hospitals, etc.

It is our experience that there are some pre-existing informal networks across England who are working in a range of ratios but there is a large distance from all networks working at the 5:1 ratio that would eliminate the gap in doctor numbers.

Where work has been done with developing networks to make designation decisions about the levels of hospitals within the networks, there is a range of ratios emerging. There are ratios of around 3:1 or 4:1 and occasionally 5:1, but there are also differences around the split of Levels 1 and 2 within a network. Although this is much better than the informal networks, a substantial gap often still remains for both medical and nursing staff.

## References

- <sup>1</sup> *Project 27/28, Confidential Enquiry into Stillbirths and Death in Infancy*, April 2003
- <sup>2</sup> Riley K, Wyatt JS, Roth S, Sellwood M. *Changes in survival and neurodevelopmental outcome in 22 to 25 week gestation infants over a 20 year period* (abstract). *Pediatric Research*. 2004; 56(3): 502
- <sup>3</sup> *Neonatal Intensive Care Review – strategy for improvement*, DH, April 2003
- <sup>4</sup> *Standards for Hospitals Providing Neonatal Intensive & High Dependency Care*, British Association of Perinatal Medicine, 2001. [www.bapm.org.uk](http://www.bapm.org.uk)
- <sup>5</sup> *National Service Framework for Children, Young People and Maternity Services, Standards for Hospital Services*, DH, April 2003 [www.dh.gov.uk/childrensnfs/](http://www.dh.gov.uk/childrensnfs/)
- <sup>6</sup> *National Service Framework for Children, Young People and Maternity Services, Standards for Children and Maternity Services*, DH, October 2003 [www.dh.gov.uk/childrensnfs/](http://www.dh.gov.uk/childrensnfs/)
- <sup>7</sup> *Neonatal Services – are they improving?*, BLISS, May 2005
- <sup>8</sup> Marlow N, Wolke D et al. *Neurologic and developmental disability at six years of age after extremely premature birth*. *New England Journal of Medicine*, 352:9-19, 2005
- <sup>9</sup> Rushe TM, Rifkin L, et al. *Neurophysical outcome at adolescence of very preterm birth and its relationship to brain structure*. *Developmental Medicine and Child Neurology*: 43: 226-233. 2001
- <sup>10</sup> Redshaw ME, Harris A, Ingram JC. *Delivery Neonatal Care: the neonatal unit as a working environment: a survey of neonatal nursing*. London HMSO. 1996
- <sup>11</sup> *Childhood, infant and perinatal mortality*, series DH 3 no 36. National Statistics 2005
- <sup>12</sup> *NHS Maternity Statistics, England: 2003-04*, National Statistics
- <sup>13</sup> *Health Statistics Quarterly*, Summer 2005. National Statistics
- <sup>14</sup> *Health Statistics Quarterly*, Winter 2004. National Statistics
- <sup>15</sup> *Stillbirth, Neonatal and Post-Neonatal Mortality, 2000 – 2003*, CEMACH 2005
- <sup>16</sup> *General Register Office for Scotland*, (provisional figures for 2004), Table P2. 2005
- <sup>17</sup> *UN Millennium Development Goal Indicators 2003*. [www.undp.org/hdr2003/indicator](http://www.undp.org/hdr2003/indicator)
- <sup>18</sup> Richardus JH for The Euronatal Working Group. *Perinatal mortality and suboptimal care between 10 European regions: results of an international audit*. *BJOG*; vol 110, 97-105. 2003
- <sup>19</sup> Graafmans WC et al. *Comparability of published perinatal mortality rates in Western Europe: the quantitative impact of differences in gestational age and birthweight criteria*. *BJOG* vol 108: 1237-45. 2001
- <sup>20</sup> Sharek PJ, Powers R, Koehn A, Anand KJS. *Evaluation and development of potentially better practices to improve pain management of neonates*. *Pediatrics* 2005; in press
- <sup>21</sup> Simons S, van Dijk M, Anand K et al. *Do we still hurt newborn babies?: a prospective study of procedural pain and analgesia in neonates*. *Archives of Pediatrics & Adolescent Medicine*: 157: 1058-1064. 2003
- <sup>22</sup> Anand KJS, Hickey P. *Pain and its effect in the human neonate and fetus*. *New England Journal of Medicine* vol 317, 21: 1321-1329 1987
- <sup>23</sup> Hummel P. *Parenting the High-Risk Infant*. *NBIN*: 3(3): 88-92, 2003
- <sup>24</sup> *Community Health Professionals' Information Guide: supporting families of premature or sick babies following discharge from hospital*. BLISS 2004
- <sup>25</sup> *Neonatal Resource Study for 2001/2: NPEU*

## GLOSSARY OF TERMS

High Dependency Unit: usually a Level 2 unit but a Level 3 unit will provide some level of high dependency care.

Infant Mortality: death within 12 months per 1000 livebirths

Kangaroo Care: enable parents to have skin to skin contact by placing their baby on their chest and tucking inside their clothes.

Level 1 Unit: see appendix I

Level 2 Unit: see appendix I

Level 3 Unit: see appendix I

Neonatal Intensive Care Unit: a Level 3 unit offering the highest level of care. There will also be step down High Dependency and Special Care

Neonatal Mortality: death within 28 days per 1000 livebirths

Neonatal Network: comprises a range of units providing different levels of care, with one lead, Level 3 unit and a number of Level 2 and 1 units, depending on the needs of the locality. It is anticipated that there will be around 24 networks in England. Wales is currently reviewing its neonatal services.

PCT: Primary Care Trust

Perinatal Mortality: death within 7 days per 1000 stillbirths and livebirths

PERISTAT is a project funded by the European Union to develop perinatal health indicators to monitor and evaluate perinatal health and care. The PERISTAT indicator set will enable the surveillance of perinatal health in the EU by harmonizing indicator definitions and encouraging the collection of comparable data.

<http://europeristat.aphp.fr/fr/indicateurs/main.html>

SCBU: special care baby unit usually a Level 1 unit. NB: all levels of neonatal units offer some level of Special Care

SHO: Senior House Officer

Specialist Commissioning Groups: PCTs who are responsible for purchasing specialist services often on behalf of a network

Stillbirth: an in utero death delivering after the 24<sup>th</sup> week of pregnancy

WTE - Whole Time Equivalent: for example, a full time nurse who works 37.5 hours a week. A nurse who works 30 hours a week is a 0.8 equivalent. However, many nurses work part, so simply counting the number of individual nurses may give a falsely inflated number.

Therefore it is the practice to add together the hours worked by several part-time nurses and count them as one whole time equivalent. This is the best measure of the number of nurses available to a ward.

## Appendix I

### Figures and Definitions

#### Birth statistics

Number of births in the UK in 2003 ('000s):

England	621.40
Wales	31.40
Scotland	52.50
NI	27.70
Total	695.50

Source: Health Statistics Quarterly, Winter 2004, Office of National Statistics

#### Premature birth statistics

The UK has the highest rate of low birthweight babies in Western Europe.

Source: Birth Counts, statistics of pregnancy and childbirth Volume 2

NHS hospital deliveries in England by birthweight (2003-4) - singletons:  
Number of births between 1,000 gms - 2,499 gms: 39,000

Under 1,000gms	4,300
1,000 - 1,499gms	4,900
1500 - 1,999gms	6,900
2,000 - 2,499gms	23,800

NHS hospital deliveries in England by gestation (2003-4) - singletons:  
Estimated Number of births from 22 to 36 weeks: 42,500

22-23 weeks	300
24-27 weeks	2,800
28-31 weeks	5,000
32-36 weeks	34,400

Source: Maternity Statistics, England, Department of Health, May 2003/4

#### Survival rates (of babies born in London specialist unit)

Babies born at 23 weeks have a 42 per cent chance of survival
Babies born at 24 weeks have a 72 per cent chance of survival
Babies born at 25 weeks have a 80 per cent chance of survival
Babies born at 28 weeks have a 90 per cent chance of survival

Twelve percent of all babies born need some level of special care at birth (about 80,000) and 2.5% of all babies born need some level of neonatal intensive care (about 17,000).

**Definitions**

Premature baby: Born before 37 weeks

Moderately premature baby: Born between 35 and 37 weeks

Very premature baby: Born between 29 and 34 weeks

Extremely premature baby: Born between 24 and 28 weeks

Low birthweight baby: Weighs less than 2,500g (5.5 lbs)

Very low birthweight baby: Weighs less than 1,500gms (3.0 lbs)

**Neonatal units in the UK**

There are approximately 220 units in the UK offering neonatal intensive care, high dependency or special care.

In England, neonatal units are currently being reorganised into Neonatal Networks comprising a range of units providing different levels of care.

There are three levels of neonatal units (these are described in general terms below and are examples of categories of care but not all categories)

**Special Care (Level 1)**

Babies requiring continuous monitoring of respiration or heart rate, receiving added oxygen, being tube fed, receiving phototherapy, recovering from more specialist care.

The nursing requirement for special care is that one nurse should not have responsibility for more than four babies, ie 1:4 nursing.

**High Dependency Care (Level 2)**

Babies receiving nasal continuous airway pressure but not fulfilling any of the categories for intensive care, any baby below 1,000gms who does not fulfill any of the categories for intensive care, babies receiving parenteral nutrition, with apnoea requiring stimulation.

The nursing requirement for high dependency care is 3.5 nurses per cot allowing 1:2 nursing.

**Intensive Care (Level 3)**

For babies needing respiratory support (ventilation); for babies weighing less than 1,000 and/or less than 28 weeks receiving nasal continuous airway pressure; with severe respiratory disease, who require major surgery.

The nursing requirement for intensive care is a ratio of 5.5 nurses per cot allowing one to one nursing.

## Appendix II

### Unit Survey Responses

Country	Number of Neonatal Units	Number of responses	% Response rate
England	182	128	70
Scotland	15	12	80
Wales	14	8	57
N. Ireland	7	5	71
All units	218	153	70

**Table I Responses to NPEU unit survey by country and overall**

## Appendix III

### BLISS/NPEU Parent Survey 2005

#### 1. Details of survey respondents to BLISS web-site survey

##### Identity of survey respondents

Q completion	Number	%
Mothers	132	88.00
Fathers	9	6.00
Both parents	4	2.67
Other	0	0
Unknown	5	3.33
Total	150	100

(Only 145 respondents completed the questionnaire properly, some of the others may not have been parents at all)

**Ethnicity of respondents:** 95.17% (138) White, 2.07% (3) Black British, 2.07% (3) Indian and 1.38%(2) Bangladeshi (n=145)

**Previous experience with baby in NNU** 8.73% (n=126)

##### Age of respondent mothers:

Age group	Number	%
<20 years	4	2.76
20-25	26	17.93
26-30	36	24.83
31-35	53	36.55
36-40	20	13.79
>40	6	4.14
Totals	145	100.00

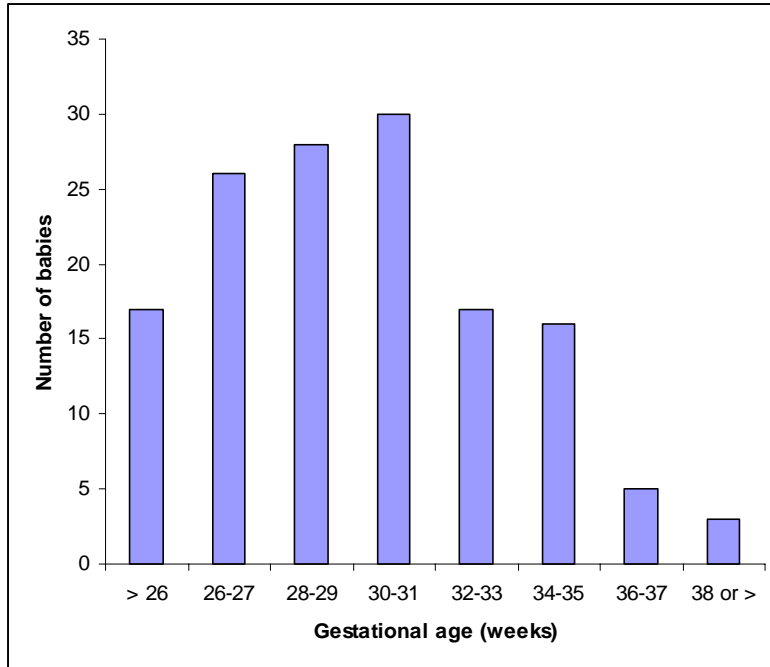
#### 2. Details of babies born to parents who responded to the BLISS survey

The data are based on the first 150 responses. Not every parent responded to every item and the numbers on which the percentages are based are shown in each table.

Parents (n=143)	
119	83.24% singletons
22	15.38 % twins
2	0.8 % triplets

ie. 16.78% multiples

<b>(n=142)</b>		<b>Gestational Age</b>
mean		29.68
s.d.		3.64
range		23-42
median		29



Distribution of babies by gestational age

<b>Duration of stay in hospital (total days)</b>	
<b>(n=142)</b>	
56.65	<i>mean</i>
35.39	<i>s.d.</i>
56	<i>median</i>
4-140	<i>range</i>



## Appendix IV

### BAPM 2001 Standards on Staffing

The BAPM staffing standards are based on two key factors; the level at which the unit operates (Intensive care, High dependency, or Special care) and the number of cots for each level of care. The formula that underpins the BAPM standards is set out below together with the average wage costs used.

#### Formula for calculating nursing establishment to BAPM 2001 Standards

*Establishment (WTEs) = ((no. IC cots) + (no. HD cots/2) + (SC cots/4) + 1) x 5.75*

Resource Calculator pre-sets (based on BAPM 2001 guidelines)										
Medical Staff Requirements (WTE)										
	Consultants		S.Reg / Middle Grade				SHO			
IC & HD & SC	7.0	fixed	8.0	+	4.0	if IC cots > 12	8.0	+	0.0	if IC cots > 12
HD & SC	1.4	fixed	1.4	+	0.0	if HD +SC cots > 20	4.0	+	2.0	if HD +SC cots > 20
SC only	0.4	fixed	0.5	+	0.0	if SC cots > 0	0.0	+	0.0	if SC cots > 0
Wage	£100,000		£48,000				£44,000			
Nursing Staff Requirements (WTE)										
							Nursing Admin		Wage	
IC	Number of cots *		5.75	/		1	+	5.75		£34,000
HD	Number of cots *		5.75	/		2	+	if IC or HD cots > 0		£30,000
SC	Number of cots *		5.75	/		4	+	if just SC cots > 0		£26,000
Nursing staff calc is equivalent to: $5.75 (ICcots + (HDcots) / 2 + (SCcots) / 4 + (if (ICcots \text{ or } HDcots > 0) \text{ then } + 1 \text{ else if } (SCcots > 0) \text{ then } + 0.5))$										

## **Appendix V**

### ***Unit costs***

The average wage costs are based on costs presented in 'Unit Costs of Health and Social Care' (Netten et al 2004), which is used by the Department of Health and HMT Treasury to calculate many of their costing estimates.

All costs are presented in 2004/5 prices and are based on:

- Wages/salary
- On-costs (national insurance and superannuation)
- Qualifications (annual costs annuitised over expected working life)
- Overheads
- Adjustment to reflect those staff receiving London weighting
- Adjusted for the grade distributions within NICU/HDU/SCBU.

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